Thinking About the Future: Life After a Diagnosis of Dementia

By

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A thesis submitted to the Faculty of Graduate Studies
Lakehead University
in partial fulfillment of the requirements for the degree of
Master of Health Sciences, specialization in Gerontology

Thunder Bay, Ontario, Canada, 2020

Author’s Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

The purpose of this research was to explore people living with dementia's perceptions of the future since being diagnosed. Research on the experiences of people living with dementia focuses on key aspects such as diagnosis, coping, relationships, and stigma. However, the sole experiences of those living with dementia is not often a focus. Therefore, five individuals living with dementia were recruited to participate in three to four focus groups to share their experiences living with dementia and their perceptions of the future. All participants had been diagnosed with early stage dementia between one and twelve years, and were living independently in their own place of residence. Constructivist grounded theory was utilized for this research with two theoretical frameworks: social citizenship and biographical disruption. Social citizenship informed this study and was the reason that only those living with dementia were included. Furthermore, biographical disruption was utilized to conceptualize the use of individuals' biographies throughout their journey living with dementia. Themes identified in this study included: "making the best of it", "I'm still capable", "finding solidarity", "life is ahead of me", "the future is measured by pivotal moments" and "the future depends on relationships and family". It was found that perceptions of the future had been influenced over time, and two broad meanings of the future emerged. There was both a present future and a distant future.

Acknowledgments

I wish to express my deepest appreciation to my thesis supervisor, Dr. Elaine Wiersma, for her wisdom and guidance throughout this journey. Elaine, your expertise in this field and passion for those living with dementia has truly inspired me to not only conduct this research, but continue in this field. Your mentorship and guidance has been instrumental to my research and I cannot thank you enough for your support.

I would also like to extend my deepest appreciation to my committee members Drs. Lynn Martin, Kathy Kortes-Miller and Nisha Sutherland. You have provided me with encouragement and patience throughout this research process. Your support and guidance was crucial to my success, and you have pushed me to be a better researcher. I cannot begin to express my thanks to all of you.

I also wish to express my sincere thanks to the staff at the Centre for Education and Research on Aging & Health (CERAH). It has been a pleasure to work with you throughout my graduate assistantship. The opportunities that you have provided me with to learn about dementia and palliative care were instrumental to my research and continuation in this field.

To the participants of this study, I want to express my deepest appreciation. Thank you for sharing your experiences and knowledge with me. You were instrumental to my study, and have inspired me to continue working with people living with dementia.

Lastly, I want to thank my family and friends. To my family, your belief in me never waivers and your support and encouragement is what inspires me to continue on this journey. To my thesis partner Emilie who has been on this journey with me, I have enjoyed all of our work sessions and the friendship that we have created since starting our masters together. Finally, Shauna and Carlina you have been incredible mentors. I had connected with you when I started my masters to help me navigate administrative tasks, and I am so grateful that I walked away with two great friendships.

Dedication

This research is dedicated to my grandparents:

Elaine Harris

Wilf & Betty Nubel

Table of Contents

AUTHOR'S DECLARATION III

ABSTRACT IV

ACKNOWLEDGMENTS V

DEDICATION VI

CHAPTER 1: INTRODUCTION 1

1.1 BACKGROUND 1

CHAPTER 2: THEORETICAL FRAMEWORKS 4

2.1 SOCIAL CITIZENSHIP: ADDRESSING STIGMA 4
2.2 BIOGRAPHICAL DISRUPTION 10

CHAPTER 3: LITERATURE REVIEW 15

3.1 INTRODUCTION 15
3.2 RECEIVING A DIAGNOSIS 16
3.3 COPING 19
3.4 RELATIONSHIPS 21
3.5 THINKING ABOUT THE FUTURE 22

CHAPTER 4: METHODOLOGY 33

4.1 INTRODUCTION 33
4.2 RESEARCH DESIGN 34
4.3 RECRUITMENT/PARTICIPANTS 36
  Description of Participants *38*
4.4 CONSENT 39
4.5 DATA COLLECTION 40
4.6 DATA ANALYSIS 43
4.7 COVID 19 IMPLICATIONS TO DATA COLLECTION 45
4.9 PERSONAL REFLECTIONS 48
  Data Analysis *48*
  Researcher Positionality *49*

CHAPTER 5: FINDINGS 53

5.1 MAKING THE BEST OF IT 56
  5.1.1 It could be worse *57*
  5.1.2 "I Had to Accept What I Had to and Move Forward": Accepting Dementia *59*
  5.1.3 "I Think You Learn from What You See": Learning from the Past *62*
  5.1.4 "You Could Play Hide and Seek with Yourself": Using Humour to Make the Best of It *65*
5.2 "WE CAN DO THINGS": I'M STILL CAPABLE 67
5.3 "YOU'RE NEVER GOING IT ALONE": FINDING SOLIDARITY 71
5.4 "A LOT OF OUR LIFE RIGHT NOW IS PLANNING AHEAD": LIFE IS AHEAD OF ME 75
  5.4.1 Carrying on *76*
  5.4.2 Staying socially engaged *78*
  5.4.3 Charting a new path *79*
5.5 THE FUTURE IS MEASURED BY PIVOTAL MOMENTS 82

5.6 THE FUTURE DEPENDS ON RELATIONSHIPS AND FAMILY 85

CHAPTER 6: DISCUSSION 90

6.1 COPING WITH DEMENTIA 90
6.1.1 Making the Best of It 90
6.1.2 Finding Solidarity. 91
6.1.3 Life is Ahead of Me 91
6.2 STIGMA AND DEMENTIA 92
6.2.1 I'm Still Capable 92
6.2.3 The Future is Measured by Pivotal Moments. 94
6.2.4 The Future Depends on Relationships and Family 94
6.3 BIOGRAPHICAL DISRUPTION 96
6.3.1 Biographical Disruption: Current literature 98
6.3.2 Time. 99
6.4 SOCIAL CITIZENSHIP 100
6.5 THEORETICAL IMPLICATIONS 102
6.6 IMPLICATIONS FOR PRACTICE 103
6.7 IMPLICATIONS FOR FUTURE RESEARCH 104
6.8 LIMITATIONS 106
6.9 KNOWLEDGE TRANSLATION 107

CHAPTER 7: CONCLUSIONS 109

REFERENCES 1
APPENDICES 8
APPENDIX A - ALZHEIMER'S DISEASE PAMPHLET 8
APPENDIX B - NICE CAPACITY FRAMEWORK 9
APPENDIX C - VISUAL AIDS 10
APPENDIX D - FOCUS GROUP GUIDE 12
APPENDIX E – ETHICS APPROVAL LETTER 14
APPENDIX F- VERBAL RECRUITMENT SCRIPT 15

.... 15

APPENDIX G - 16
INFORMATION LETTER FOR THINKING ABOUT THE FUTURE: LIFE AFTER A DIAGNOSIS OF DEMENTIA 16

.... 16

.... 21

APPENDIX H - VERBAL CONSENT SCRIPT 21

.... 22

APPENDIX I - FOCUS GROUP GUIDE (AMENDED) 22

Chapter 1: Introduction

1.1 Background

To date, there are more than 500,000 people living with dementia in Canada; a number expected to increase 66% by 2031 (Alzheimer Society of Canada, 2018b). The Alzheimer Society of Canada (2018a) defines dementia as:

> an overall term for a set of symptoms that are caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour. (para. 1)

Dementia in all its forms is typically considered a life-limiting condition, that is, a condition that is expected to shorten one's life span, impacts daily life, and has no cure. A diagnosis of dementia has significant implications for the individual, family/support networks, and society (Wiersma et al., 2016). (For further information regarding dementia, including its history and different forms, please see Appendix A).

Dementia is associated with negative perceptions, and many people with dementia experience stigma as a result (Burgener et al., 2015). The Alzheimer Society of Canada surveyed 1,506 Canadians about Alzheimer's disease and other forms of dementia and found that: "Canadians acknowledge that people living with dementia regularly experience many forms of stigma" (Alzheimer Society of Canada, 2019a, para 2). Part of this study reported what they called self-imposed stigma (Alzheimer Society of Canada, 2019a). Fifty-six percent of participants feared being a burden to others, losing their independence, and not recognizing family and friends. Half of participants feared not being able to live well, and 27% feared their life would be over. One in five participants said they would avoid seeking help to escape stigma (Alzheimer Society of Canada, 2019a). In short, people have negative perceptions of dementia, mostly tied to fears of the future. As such, stigma of dementia played an important role in meanings and perceptions of the future once dementia entered an individual's life. Understanding more about how people living with dementia themselves think about the future is important in supporting people to live well throughout their dementia journey.

While dementia is a life-limiting condition, it has not typically been treated as a chronic condition. Kydd and Sharp (2016) suggested that dementia should be seen as—a chronic illness ensuring that services are focused on living well with the condition, a disability so services are focused on inclusion both physical and social, and a terminal illness so services will focus on a good death. Despite the concerns expressed by Kydd and Sharp, theories related to chronic illness can provide important insights into the dementia experience. For instance, experiencing a chronic illness may also cause disability and be considered life-limiting, and as such, I do not see these categories as mutually exclusive. The chronic illness literature, disability literature, and palliative care literature can all provide important insights and frameworks to conceptualize dementia and dementia care.

My research examined dementia with two conceptual frameworks. Firstly, social citizenship (Bartlett & O'Connor, 2010) was used to shape the methodology and challenge the stigmatization of dementia. In addition, Michael Bury's (1982) biographical disruption theory, which utilizes people's biographies to explain the experience of chronic illness, was used to conceptualize how perceptions can be influenced over time and by one's experiences. Biographical disruption views people's lives as a story, and examines the diagnosis as a disruptive event that changes the trajectory of a person's life and of his or her story (Bury, 1982).

This is amplified in dementia, because it is not just chronic, but life-limiting. As such, a diagnosis of dementia means rethinking the future. As one poignant film about dementia produced by Dementia Australia suggested in its tag line: “My life hasn’t ended. Just the ending has changed” (2014).

Specifically, the purpose of this research was to explore people with dementia’s perceptions of the future since receiving their diagnosis. Perceptions of the future are not solely shaped by individuals, but are influenced by various factors, including others (family, care partners, friends, community, services and supports) (Bury, 1982), personality characteristics that aid in coping (Kitwood, 1997b), experiences in social environments such as stigma, past history, and a variety of other factors (Beard, 2004b).

Therefore, the specific research questions included:

1) What does the future mean to people living with dementia?
2) Do people’s perceptions of the future change with a diagnosis of dementia? If so, how and why? If not, why not?
3) What helps people living with dementia cope with their diagnosis and the changes they may be experiencing?
4) When people with dementia think about the future, who are the people they want to be involved? If there are people not included, why? And,
5) What does stigma mean to the person living with dementia and how does this influence their perceptions of the future?

Chapter 2: Theoretical Frameworks

2.1 Social Citizenship: Addressing Stigma

Two important theories guided this work, social citizenship and biographical disruption. First, the concept of social citizenship is the overarching philosophy through which I approached this research. Social citizenship provided an important lens through which to view the experiences and behaviours of people living with dementia—that is, providing an understanding of not only how people with dementia react to experiences and circumstances, but how they create their own meaning in their lives, how they respond to and shape experiences and circumstances in their lives, and how they influence others around them (Bartlett & O'Connor, 2010). Social citizenship, particularly in everyday circumstances, sensitizes others to see people with dementia as active agents in their lives, not merely as recipients to events and activities.

Not only was this philosophy critical to shaping the methodology (i.e., that of including people living with dementia as co-producers of knowledge), but social citizenship also recognizes that people living with dementia are not passive recipients to the events occurring in their lives. Rather, they adapt to and cope with situations, but perhaps more importantly, they continue to shape and influence events and people around them, both in everyday interactions and for some, at broader public and policy levels (Bartlett & O'Connor, 2010; Bartlett, 2014). Social citizenship informed this research study by ensuring that attention was paid to the ways in which people with dementia shape, and are shaped by, situations in their lives.

The importance then of learning from those diagnosed with dementia was imperative to challenging issues of stigma that currently do not place emphasis on their experiences. When people with dementia share their stories, it challenges the assumption that a diagnosis of dementia is synonymous with loss (Beard, 2004b). If peoples' worth or sense of identity is based solely on their cognitive abilities, then we will surely continue to limit people with dementia and devalue their experiences as individuals. Moreover, Beard (2004b) argued the widespread misconception that people with dementia are incapable of communicating effectively compounded the stigma around their condition. Communicating differently does not mean that one is unable to communicate. People with dementia have ways of adapting their communication styles, if need be, to exert power within their social lives (Bartlett & O’Connor, 2007).

Although memory loss is often associated with aging, dementia is not a part of the normal aging process (Alzheimer Society of Canada, 2018c). Societal views about the value of mind over that of body are influenced by biomedicine (Beard, 2004b) and are intrinsically linked to dementia studies. The nature of bio-medicine: “engenders a separation of physical, psychological, and cultural dimensions of aging” (Beard, 2004b p. 416). There is no arguing the importance of medicine and curative treatments, however, those approaches leave much unattended to. Medicine is incapable of, and not responsible for reading into the context of individuals’ circumstances and is: “left with the impossible task of trying to meet (emotional) needs of ‘patients’ that are beyond its jurisdiction. Furthermore, it threatens to exacerbate an antiaging mentality where biomedicine ultimately aims to ‘cure’ aging itself” (Beard, 2004b p. 416). Dementia cannot be cured, and as a result we should support their ability to live a fulfilled life with their condition. To do this successfully, we need to consider psychosocial aspects of life (such as relationships, identity, social structures, to name a few) and how impactful they can be. Learning how those living with dementia could be affected by their interactions with others and society directly relates to the stigmatization of their condition. Understanding the effects of stigmatization on people living with dementia is crucial if we are to change the way dementia is perceived, and how people are treated as a result.

As a society, we perpetuate the stigma surrounding dementia. Link and Phelan (2001) believed stigma could be described as existing: “when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold” (p. 382). An example of society perpetuating the stigma surrounding dementia is when organizations do not rely on honest accounts of people living well with dementia because they do not appeal to the public for support, and do not bring in significant donations for organizations that are campaigning for Alzheimer’s movements (Beard, 2004a). By emphasizing the stories of people who are living well with dementia, it leaves the potential for others to perceive that their condition is not challenging (Beard, 2004a). Beard (2004a) found that this has impacted the way some Alzheimer Societies are able to raise awareness and gain funding, and stated that there: “exist inherent biases…in favour of bio-medical aims and caregivers as the primary clients” (p. 815). This relates to the stigma of not only dementia but other mental health issues. If people cannot see the physical representations of a limiting condition, it may be perceived as though it is not impactful on someone’s life, and thus not worth the time or money that other chronic and life-limiting conditions are able to obtain. The result of such practices was easily recognized when one examined the amount of funding that goes towards: “cause and cure’ research, caregiver consequences and long-term care policies” (Beard, 2004a p. 799).

In addition, the widespread practice of proxy reporting—taking care partner or health professional perspectives and comparing them to the perspectives of those living with a cognitive impairment—further contributed to stigmatizing those with dementia (Beard, 2004b). Beard (2004b) argued that proxy reporting contributed to their lack of involvement as participants in research because of perceived inability or fear of harming them. Enabling people with dementia to speak about their experiences is one of the most impactful ways to change policy; and people with these conditions have shown their willingness to do so (Beard, 2004b).

Furthermore, Sweeting and Gilhooly (1997) conducted a study that examined whether relatives of people who were diagnosed with dementia perceived them as socially dead. Sudnow's definition of social death as cited in Sweeting and Gilhooly (1997) is: "that point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for treating him, and when he is essentially regarded as socially dead" (p. 94). The authors identified people who are considered 'very old', have a 'lengthy terminal illness', or who have lost their 'personhood' as individuals that were more likely to experience social death (Sweeting & Gilhooly, 1997 p. 95). The authors believed people living with dementia are at risk of social death because the condition is terminal, occurred most often in elderly people and the stigma surrounding dementia could be linked to a loss of personhood (Sweeting & Gilhooly, 1997).

In their study, 100 relatives of people with dementia were asked questions that would distinguish whether they believed their relative was socially dead, they behaved as if they were, or a combination of the two (Sweeting & Gilhooly, 1997). Interview questions consisted of themes such as how much the carer believed the person with dementia was aware of their surroundings, the importance of their dignity, the belief that they should be treated as a person, whether or not they anticipated their death and whether it was a positive or negative outcome, and finally, the perceived value of the person's life who was living with dementia (Sweeting & Gilhooly, 1997). Of those interviewed, slightly more than one third believed and behaved as if their relative was socially dead, one fifth believed they were but did not behave as such, and a very small number (4) behaved as if they were socially dead but did not believe they were

(Sweeting & Gilhooly, 1997). This is an important topic to address, because much research has been done around the stigmatization of people with dementia. It is clear to see that perceptions of social death—which can lead to the stigmatization of those living with dementia—are barriers to advocacy and advancement in the treatment of people living with dementia. As such, these will be important areas to address with the participants of this study, as these are seemingly inescapable experiences which could have an impact on how they think about the future.

Bartlett and O'Connor (2007) explained how personhood and citizenship could be used to challenge the stigmatization of people living with dementia. Firstly, personhood has functioned as a: "critical component of the dementia experience. Challenging traditional understandings which linked it solely to cognitive functioning, personhood was re-envisioned as socially constructed by and within one's interactional environment" (Bartlett & O'Connor, 2007 p. 109). Kitwood's (1997a) original definition of personhood in the context of dementia defined it as a status bestowed on a person by others in the context of relationships. Personhood recognizes the essence of who one is, one's identity, and respecting the individual as such. In addition, the theory of citizenship: "is used to promote the status of discriminated groups of people to that of an equal citizen, with the same entitlements as everyone else" (Bartlett & O'Connor, 2007 p. 108). In particular, a citizenship approach brings awareness to human rights (Cahill, 2018). To date, personhood has dominated dementia literature over citizenship which the authors proposed could be due to the difference between personhood and citizenship not being clearly distinguished, and citizenship's emphasis on a person's self-awareness, that could pose potential problems for late stage dementia (Bartlett & O'Connor, 2007). Personhood in very individualized, and citizenship extends that to broader public and policy levels. This is an important concept when examining the impact of stigma, because we need to not only focus on the person and their immediate interactions, but how they interact within broader social structures (medical, education, political, etc.). Link and Phelan’s (2001) work on stigma is important to this idea because they believed in order to challenge stigma, efforts needed to be multi-level and multi-faceted. To change stigma, we must address the beliefs of those who have power that lead to stigmatization or limit the power of those groups so their beliefs are not dominant (Link & Phelan, 2001).

Personhood has undoubtedly benefitted people living with dementia. It has challenged stigma in many ways including changing discriminatory language and encouraging their participation in research and practice (Bartlett & O’Connor, 2007, 2010). Bartlett and O’Connor (2007, 2010) stated that personhood has refocussed attention on the individual living with dementia, and allowed people to see life beyond the diagnosis. As much as this theory has benefitted dementia research and practice since its inception in the 1980s, it has limitations in promoting the empowerment of people living with dementia (Bartlett & O’Connor, 2007). Some of these limitations include: it does not recognize the agency of people living with dementia, and its focus on the individual has ignored broader social and political structures that impact people’s lived experience (Bartlett & O’Connor, 2007). Moreover, Bartlett and O’Connor (2007) stated: “Even with its revisions then, a personhood lens does not explicitly recognize a person with dementia as a social actor, capable of exerting power and influence” (p. 110). This will be an important factor in this research, as it relates to how people with dementia are not simply passive recipients of support and care, but are actively managing, coping, and rethinking their futures. People with dementia are not merely responding to what is happening to them, but are also effectively taking control, impacting and influencing circumstances, experiences, and people around them.

The ability of citizenship to extend the individualized focus that personhood has captured has also been seen: “in disabilities studies where research and practice has increasingly been dominated by the belief that it is through the process of making political the personal experiences of discrimination and social inequality the situation of marginalized groups of people can be improved” (Bartlett & O’Connor, 2007 p. 111). The ability of citizenship to more broadly address structural issues of discrimination does not mean the issues themselves have to be wide spread. In order for citizenship to work, people have to be considered ‘actors’ within their respective social settings (Bartlett & O’Connor, 2007; Branelly, 2011) regardless of where that place is (Branelly, 2011). However strongly personhood and citizenship are recognized for their importance, the authors noted that: “Personhood cannot fully explain the essence of power relations and citizenship cannot fully recognise the essence of individuality. Moreover, neither lens fully grasps the complexities of human experience, particularly the relationship between self and society” (Bartlett & O’Connor, 2007 p. 114).

2.2 Biographical Disruption

The theoretical framework of biographical disruption (Bury, 1982) guided this research and provided important insight into how dementia was conceptualized in this study. Biographical disruption, previously used in chronic illness research, aimed to examine how people were able to ‘re-story’ their lives after being diagnosed with a chronic illness (Bury, 1982). Bury’s original work on biographical disruption emerged from a study of people who had been diagnosed with rheumatoid arthritis. Bury (1982) suggested that everyone, whether consciously or unconsciously, had ideas or plans for their lives and their future. A diagnosis of a terminal or chronic condition changed one’s life course. While this theory was used in chronic illness (which is not always life-limiting) this framework was utilized for people living with dementia, a diagnosis which is also life-limiting. This framework enabled this research to not only recognize the diagnosis as the life altering event, but how that had impacted the way these individuals thought about the life that was ahead of them—their future. While biographical disruption has not commonly been used in research with people living with dementia, I chose to use this framework because of the similarities of dementia with other chronic conditions as well as the nature of this research exploring people's life stories and the future.

Furthermore, being diagnosed with a life-limiting condition required people to acknowledge decline in health, or even death (Bury 1982). Roles may change as a result of their declining health, testing the strength of their relationships (Bury, 1982). Chronic conditions would inevitably cause the diagnosed person to depend more on people for support as their condition progressed (Bury, 1982). The biographical disruption forced the person to analyze their situation and make plans for their future that they otherwise would not have had to (Bury, 1982).

At the first onset of symptoms, people looked to their external environment for an explanation; for instance, physical pain could be explained by strenuous activity (Bury, 1982). For someone with dementia, early signs could include trouble remembering; something that could be harmlessly associated with age, or being busy or overwhelmed. The importance of this stage was that there was an evaluation of the person's life that occurred (Bury, 1982) in order to explain away what was actually the onset of dementia. This external explanation of symptoms would continue until they were no longer able to account for its severity (Bury, 1982). The nature of chronic conditions, unlike communicable illnesses, is that they do not just suddenly appear, but symptoms gradually and cumulatively progress over a period of time (Bury, 1982).

Once symptoms reached a point where a person sought out help, they may have considered obtaining medical advice (Bury, 1982). Biographical disruption explained that during this stage those diagnosed with rheumatoid arthritis experienced anxiety and disbelief, believing they did not meet the benchmarks for someone diagnosed with this condition (Bury, 1982). Most people do not want to feel as though they have become isolated in a time of vulnerability and uncertainty. The inability to predict the trajectory of life after being diagnosed with a life-limiting condition is described as a biographical shift, and could be challenging for people to navigate (Bury, 1982). Once there is a confirmation of a chronic condition, questions about one's future could potentially arise.

When faced with the uncertainty of their chronic condition, an important aspect of biographical disruption occurred when the person's access to medical knowledge enabled them to separate themselves from the condition (Bury, 1982). It was difficult for people to separate themselves from a condition when they were experiencing its effects in all areas of their life (Bury, 1982). Much the same as a diagnosis of rheumatoid arthritis, dementia has no cure. Therefore, those diagnosed have to come to terms with the idea that they will live with this condition for the remainder of their life. It is important that the healthcare system provides people with as much education, assistance and alleviation of symptoms as possible, however, there is no quantitative measure that will ever come close to managing the social impact a condition has on someone's future (Bury, 1982). This is where the supporters of those diagnosed need to empower and support the person in making sure they continue to be involved in their future.

Attaching a name to the illness was also an extension of this biographical disruption (Bury, 1982). In one way, people felt comforted to know that there was justification for the symptoms they were experiencing, but conversely, they recognised that medicine could not fix their condition (Bury, 1982). Therefore, they were forced to rely on their own knowledge and biographical experience to fill in the gaps (Bury, 1982). Bury (1982) stated individuals often reflect on life events in order to explain the possible origin of the condition. Trying to connect personal life experiences and knowledge to one's illness was seen as a way of coping, because it could provide justification of the condition in the absence of medical knowledge (Bury, 1982).

Thus far, we have examined the theoretical underpinnings of biographical disruption from onset of symptoms to diagnosis. From here the person now has to start living with the intrusion of the condition into their everyday lives. Bury (1982) referred to this stage as the mobilisation of resources. Bury (1982) described that relationships can be disrupted not only because of changes in a person's ability, but a person with dementia may also have a feeling of self-consciousness that their condition may create. For people with dementia this is a very real experience. For instance, progressive cognitive decline will become harder for people to hide from those close to them. Withdrawing from social circles and family can become an attempt to hide their diagnosis, and appear normal to others in fear they may be judged (Bury, 1982). Bury (1982) has explained this act of maintaining an image of normality as something that required a great deal of effort, and could be hard for people maintain. This is important for the mobilisation of resources because it was people's immediate support, and those who spent the most time around the individual who would notice the changes in behaviour first. When people were aware that symptoms of the condition were visible, there was an attempt to mask that disruption of normal behaviour from others (Bury, 1982). This can be linked to loss of friends and family, but also jobs and activities. The success of normalisation in social settings, he further clarified, required flexibility from those around oneself as well as formal institutions, in order to remain a participant in usual activities as long as possible (Bury, 1982).

In summary, medicine is capable of describing physical characteristics to be expected of chronic conditions, but it cannot provide individuals with the knowledge of how other psychosocial factors would impact them as a result of their diagnosis (Bury, 1982). Bury (1982) further explained that medical information about one's chronic illness was important, but it only tells us about the illness itself; it does not tell us for certain how impactful it could be on one's future. People who are diagnosed with a life-limiting condition such as dementia have to be able to utilize both physical and cognitive resources in order to 're-story' their life after diagnosis (Bury, 1982). It is in the re-storying of people's lives that we have the potential to see the agency and citizenship of people with dementia in facing the future. That is why examining life experiences/biographies was important, because it illuminated the most important aspects of the future and ultimately how their perceptions of the future could be affected. Between the theories of biographical disruption and social citizenship, it allowed the researcher to take into consideration how impactful receiving a diagnosis could be, and how people could be able to adjust and incorporate dementia into their lives. Individuals with dementia were active agents that influenced how other people thought about them, how they participated in their care, and were able to act on their perceptions of the future. The following areas will be addressed in the literature review to provide a background for the proposed study:

- receiving a diagnosis of dementia (conceptualized as a 'biographical disruption');
- adapting and adjusting to the dementia diagnosis;
- relationships in the dementia context, and
- decisions about the future (brief overview of how decisions are made)

Chapter 3: Literature Review

3.1 Introduction

The development of this project was a result of collaboration with my supervisor (Dr. Elaine Wiersma), and acknowledging that there is a debate about palliative approaches to care for people with dementia. In addition, it was important to me that I conducted a study that directly involved people living with dementia based on my personal experiences. First, biographical disruption (Bury, 1982) was recommended, and adapted as a theoretical framework to examine how people living with dementia conceptualize their future after receiving a diagnosis. With that framework, I started the literature search by identifying the prominent authors in dementia research. Studies done by those authors identified recurring themes of stigma, diagnosis, relationships, and living well with dementia. Similarly, there was a recognition that the experiences of people living with dementia were seldom the sole focus of research; often being reported alongside the perspectives of care partners.

A search strategy was conducted that looked for research that provided the perspectives of people living with dementia, and how they thought about their future, with the aforementioned social perspectives and circumstances that could affect their perceptions. Resulting from those searches in databases such as (PubMed, CINHAL, ProQuest, and Medline) were articles that spoke to medical decision making rather than conceptualizations that incorporated life and social circumstances; which would capture the future more broadly. However, those articles were not excluded. Included in the review is a section of literature on the ways that decisions are made when someone has been diagnosed with dementia. As dementia is a life-limiting condition, I felt it was important to recognize that death may be a topic that people with dementia could bring up when asked about their thoughts regarding their futures; however, this did not address my research objectives. The objective of this research was to more broadly address how people living with dementia think about their future and what could influence those perceptions. Because I did not want to assume what held the most importance in their future, I included a broad overview of literature that prepared me for various discussions. This research was directed by participants, and it was important that questions were broad so as to not influence topics of conversation.

It was this rationale that influenced the decision to not focus on medical, palliative or any care approaches and whether people with dementia wanted to talk about those topics, but rather to ask them more broadly, ‘how do you think about your future since receiving a diagnosis?’. By utilizing open ended questions and allowing the participants to interpret them, it enabled me as researcher to consider social and life circumstances such as the process of receiving, adjusting, and coping with a diagnosis, stigma, relationships, and living well. This literature review was focused on sections that outlined the various aspects of biographical disruption—receiving a diagnosis, adjusting to and coping with a diagnosis, living well with a diagnosis, relationships after a diagnosis, and decisions about the future. Biographical disruption focuses on peoples' biographies and how they tell the story of living with dementia. The examination of peoples' stories helped uncover what was most important about their future, and how they perceived living with dementia moving forward.

3.2 Receiving a Diagnosis

Understanding the perceptions of people living with dementia in regards to their future meant that an overview of receiving a diagnosis was important to provide context. However, once people do seek help, some individuals may not always be told about their diagnosis

(Bamford et al., 2004). Once the diagnosis is received, individuals reported various experiences and responses to receiving this diagnosis (Pratt & Wilkinson, 2003; Robinson, Clare, & Evans, 2005; Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). Pratt and Wilkson (2003) asserted that disclosing a diagnosis of dementia required medical professionals to consider how much information to give, the ability of the person to receive the information and the social context in order to minimize the distress of the person being diagnosed.

The advantages and disadvantages associated with disclosing a diagnosis of dementia were often debated (Robinson et al., 2005; Vernooij-Dassen et al., 2006) including the amount of information that physicians provided (Bamford et al., 2004). The preferences of people with dementia in regards to knowing their diagnosis was not commonly found in the literature (Bamford et al., 2004) but their preferences and social context were important factors when disclosing a diagnosis of dementia (Pratt & Wilkinson, 2003). Most importantly, stigma had greatly impacted people's decision to disclose their condition (O'Connor, Mann, & Wiersma, 2018; Pratt &Wilkinson, 2003) for fear they would be excluded or treated differently (O'Connor et al, 2018).

As with any progressive condition, there is typically the need to readjust to symptom severity, and the impact it has on daily life. In the case of dementia, people described their identities in two ways 1) attempting to maintain how they defined themselves before the diagnosis and 2) adjusting and combining new aspects of their identity after being diagnosed (Harman & Clare, 2006). This cyclical process can be divided into two stages, one that aims to maintain who the person believed themselves to be before the diagnosis, and one that aims to integrate how the diagnosis has changed them (Harman & Clare, 2006). After receiving a diagnosis people were forced to make sense of the news (Robinson et al., 2005) and balance struggling with its effects and maintaining a fulfilling life (Harman & Clare, 2006). Chronic illness theories can be helpful in studying dementia because they examine the effects it has on the individual (Harmon & Clare, 2006). This was another reason why biographical disruption—which arose out of chronic illness literature— was used as a conceptual framework for this research. It captured how impactful a diagnosis of dementia could be on an individual by examining how they told their stories in relation to their biographies.

The differences people might see in themselves while completing routine tasks is a key indicator of the implications that chronic conditions might have on them (Harman & Clare, 2006). Adapting to a chronic condition required the individual to acknowledge changes in themselves as a result of their diagnosis (Harman & Clare, 2006). This research study would take this one step further, as chronic illness theory only focussed on conditions that are progressive and typically physical in nature, but not necessarily life-limiting or affecting cognition. The idea is that life-limiting cognitive conditions are a disruptive life event that require adaptation and coping strategies, but then individuals diagnosed with the condition move towards planning for a future that has undoubtedly changed its direction.

Furthermore, Aminzadeh, Byszewski, Molnar, and Eisner (2007) interviewed care partners and those who received a diagnosis of probable Alzheimer's or vascular dementia over four months to examine the emotional impact of the diagnosis and its disclosure. Both groups noted the impact of losses since being diagnosed, both the ones they have already dealt with and the ones presumed to come in the future (Aminzadeh et al., 2007). Medicine, as a discipline, has afforded people the opportunity to be diagnosed earlier (Aminzadeh et al., 2007; Steeman, de Casterle, Godderis, & Grypdonck, 2006), and thus the potential is there to better understand the experiences of being diagnosed and living with dementia, and support people in this (Aminzadeh et al., 2007). Some of the symptoms of dementia may pose potential problems in the adjustment and coping abilities of those diagnosed, but psychosocial (Aminzadeh et al., 2007) and societal responses also play a crucial role (O'Connor et al., 2018). Thus, understanding what a diagnosis means to someone requires a focus on many aspects of the individual's life, not just cognitive symptoms of various dementias.

3.3 Coping

Developing coping strategies is an important way that people are able to manage their diagnosis and live well. It is important to consider that individuals experience their diagnosis differently, and the ways in which people are able to cope are dependent on their personal experiences, internal resources, interpersonal relationships, as well as their environment (Kitwood, 1997b). Kitwood (1997b) recognized that people have both psychological barriers that hinder their ability to cope, and assets that improve their ability to cope. Most importantly, Kitwood (1997b) described psychosocial needs that a person living with dementia required such as: comfort, attachment, identity, occupation and inclusion. All of these related to being loved, described as the feeling when people are accepted and others do not expect anything in return (Kitwood, 1997b). Society emphasizes "cause and cure research" (Beard, 2017 p. 685), but a compassionate approach enables connection, a recognition of lived experiences, and a move beyond curative treatments.

Moreover, Harman and Clare (2006) conducted an important study that exemplified the experiences of those living with dementia. They identified two major themes related to coping: it will get worse and I want to be me (Harman & Clare, 2006). The aim of the study was to show how dementia impacted people's everyday lived experiences (Harman & Clare, 2006). It will get worse related to the individual's attempt to cope, and their understanding of dementia as a progressive illness that will continually effect their ability to function (Harman & Clare, 2006). Sub-categories expressed by interviewees within this broad theme included: their understanding of dementia, making comparisons, certainties and uncertainties, and finding ways to cope (Harman & Clare, 2006). An individual's understanding of dementia varied greatly, but were summarized into either biological or social underpinnings (Harman & Clare, 2006). Making comparisons were a form of evaluating their situation and progression by comparing themselves to others with or without dementia, or with how they recognized changes within themselves over time (Harman & Clare, 2006). Lastly, finding ways to cope were personalized ways that an individual navigated life differently after changes to normal routines (Harman & Clare, 2006). Furthermore, sub-categories of *I want to be me* included: personal dilemmas and interpersonal relationships (Harman & Clare, 2006). Harman and Clare (2006) stated: "Personal dilemmas centered on the question 'Where do I stand?'" (p. 494). Some people wanted to learn about dementia, whereas others did not want to think about it, and in regards to experiences of dementia, some fought their diagnosis while others were more accepting (Harman & Clare, 2006). This study proved the value in allowing those living with dementia to tell stories about how they perceived living with their condition.

While western medicine has reduced symptoms of dementia to solely expressions of the condition itself, Phinney and Chesla (2003) argued that symptoms are representative of the lived experience and an integral part of communicating with others. Phinney and Chesla (2003) interviewed nine people with Alzheimer's disease about coping and their experience of symptoms. It was poignantly stated: "As a culture, we think of dementia as something that affects us from the neck up, a devastating disease where the body is tragically spared" (Phinney

& Chesla, 2003 p. 285). The lived body is described as the way: “breakdown is embodied in everyday habits and practices” (Phinney & Chesla, 2003 p. 285). Three themes exemplified the way people experienced disruption of the skilled habitual body: ““Being slow” is about the lived body slowing down as activity becomes halting and tentative. “Being lost” is about people’s difficulty finding their way in an unfamiliar world. “Being blank” is about being in an empty world wherein people are unable to find the thoughts and words that make it possible for them to engage in a reflective act, and meaningful habits and practices fall by the wayside”” (Phinney & Chesla, 2003, p. 288). The importance of this study was that it moved beyond clinically viewing symptoms as solely indications of the underlying disease, and learning to interpret them as the way people communicated their experience living with Alzheimer’s (Phinney & Chesla, 2003).

3.4 Relationships

Finally, relationships have been found to have a profound effect on people that have been diagnosed with dementia. Dementia can affect interpersonal relationships, particularly in relation to how others treated them before versus after their diagnosis (Harman & Clare, 2006). This was tied directly to the stigma that people with dementia face, and its potential to lead to social exclusion (Harman & Clare, 2006). This dilemma can arise when people with dementia perceived themselves to be positioned differently within their social settings compared to how those around them perceived them to be positioned (Harman & Clare, 2006).

Furthermore, a study conducted by Johannessen and Möller (2013) utilized grounded theory to analyse the experiences of people living with early onset dementia to aid in the development of future services. The authors noted the important role that challenging stigma played for someone living with early-onset dementia (Johannessen & Möller, 2013). Participants in this study felt that as a result of people’s misconceptions, it reduced their openness/willingness to talk about their condition, hurt their self-confidence and ultimately impacted their ability to cope (Johannessen & Möller, 2013). Studies have also noted that people living with dementia may fear being a burden to others (Alzheimer Society of Canada, 2019a; Clarke, Korotchenko, & Bundon, 2012; Johannessen & Möller, 2013). Traditionally, dependency and family care have been the focus of research and thus it is important to understand how families are involved in care, and their ability to empower or disempower someone living with dementia (Wiersma et al., 2016).

One of the most prominent relationships to consider is the spouse. When facing the decision to tell their family of the diagnosis, the participants had wanted time to adjust with the diagnosis first (Johannessen & Möller, 2013, p. 418). It has been noted that the experiences a person with dementia goes through in adapting to losses and coming to terms with their diagnosis also impacted their partner (Robinson et al., 2005). The process began with the spouse noticing changes in their partner with dementia, acceptance of the situation, and realizing their ability to develop coping strategies on their own and within their relationship (Robinson et al., 2005). Ultimately, couples accepted losses and found ways to stay focussed on the abilities that remained (Robinson et al., 2005). As previously noted, planning for one’s future is not done in isolation. Understanding how people with dementia interact with family and friends, among others, is an important aspect to understanding their perceptions of the future.

3.5 Thinking About the Future

This section of the literature review provides a brief overview of how people living with dementia think about the future and then act upon those perceptions. Future planning could be conceptualized as advance care planning. Advance care planning is about discussing your future wishes for health and personal care with those close to you (family, friends etc.) (Speak Up Canada, 2020). In Canada, a substitute decision maker also plays an important role because they would make decisions for the person in the event they were no longer able to (Speak Up Canada, 2020). However, I am examining how people with dementia think about the future, and then act upon these thoughts, not solely focusing on traditional conceptions of advance care planning. The progressive nature of many dementias, coupled with the current discourse prevailing in the literature of arguing for and against a person's cognitive capacity, and ability to give consent (Appendix B) is an inescapable topic. In preparation for focus group interviews, it was important to consider that end of life may be brought up as an important aspect of planning for a future living with dementia. While methods of advance care planning are often associated with palliative approaches to care, that is not the focus of this section of literature. Rather it offers a brief description of how advance care planning may play a role in discussions about the future for people living with dementia. It is also important to note that this section of literature relies heavily on European studies as they were the ones that most often included the perceptions of those living with dementia. Therefore, this section is not reflective of the language used in Ontario's health care system. Because this research is taking place in Ontario, the concluding section of this review will address some important terms used when describing palliative approaches to care in Ontario.

Regardless of whether chronic conditions, sickness or illness are present or not in someone's life, death is a part of our future. Finding scholarly publications that present the views, opinions and experiences of people living with dementia in regards to how they plan for end of life was very difficult. There is little literature that reflected their perspectives, which is presumed to be related to the assumption that they are unable to express themselves (Beard, 2004b), or consent to research (Fetherstonhaugh et al., 2013), coupled with the stigma associated with dementia (Bartlett & O'Connor, 2007; Beard, 2004a; Beard, 2004b; Branelly, 2011; Harman & Clare, 2006; Johannessen & Möller, 2013). Moreover, the studies depicted in this review are predominantly European, as there was very little Canadian literature on advance care planning that included the perceptions of those living with dementia. Planning for a future requires people with dementia to make decisions, and if it is not them, then in fact someone else is planning their future on their behalf. Instead of first-hand accounts of thinking about the future, including the potential incorporation of palliative approaches to care, literature will be presented that summarizes the different ways decisions are made for people with dementia in order to assess their involvement in such decisions, and how potential ways of involvement could be addressed in the future. Knowing the different ways that people with dementia can act on their conceptions about the future will be important if they wish to talk about end of life.

Firstly, Dening (2015) defined advance care planning: "as a process of discussing and recording the wishes, values and preferences for future care and treatment, held between an individual and their care provider(s)" (p. 42). The presumption of advance care planning is that it is done in advance of cognitive decline before competence to make decisions would be questioned (Dening, 2015; Jones et al., 2019). However, van der Steen et al. (2014) conducted a systematic literature review on advance care planning and found that there were very few studies that reported the perspectives of people diagnosed with dementia in regards to aspects of advance care planning. Instead, most literature presented family views, but suggested that studies presenting the best information on ACPs were qualitative works (van der Steen et al., 2014). This further reinforced the importance of this study. If participants brought up advance care planning or end of life, it would be an opportunity to add their perspectives to the literature.

However, the sentiment surrounding advance care planning is the ambiguity and unsureness of the process. Some of the barriers involved in making decisions included: who is involved, the timing and process of decision-making (Jones et al., 2019) and an overall reluctance to make decisions (Jones et al., 2019; van der Steen et al., 2014). Reliance on care partners in cases of progressive conditions are inescapable. Therefore, it is important to consider what role care partners played in advance care planning, and what the involvement of the person with dementia was in the process. It is suggested that care partners may find decision-making more difficult when the person they are caring for has additional health conditions, because it amplified the life-limiting nature of dementia (Dening, 2015). Dening (2015) described this experience for care partners as challenging because it is hard to determine: “when a person stops living with dementia and starts to die with dementia” (p. 42). Furthermore, a scoping review by Jones et al. (2019) found that care partners’ choices were based on their own experiences, care partners struggled to discuss preferences of the person with dementia, and ultimately, their views were prioritized as a result. Involvement of family, timing, and the impact of discussing the life-limiting nature of dementia may impact how people think about the future.

Furthermore, some of the issues in developing advance care plans included not knowing how to adapt them to dementia, and not knowing how to start the conversation with someone (Jones et al., 2019) whose condition has an unpredictable trajectory (van der Steen et al., 2014). Development of advance care plans will require greater clarity about the process, including a better understanding of which care partners (formal/family care partners) are required to participate and when (Jones et al., 2019). Not understanding the nature of dementia, or being unsure of options when it comes to advance care planning can ultimately force care partners to make decisions in a limited amount of time should an emergency situation arise (Jones et al., 2019). With the numbers of people living with dementia rising it is important that education and training in regards to advance care planning is strengthened, and this will require effective communication between all people involved in the process (Jones et al., 2019).

In order to better advance care plans, ensure that these decisions are made in advance of crisis situations, and approached in a manner sensitive to the person with dementia's wishes, we need to address the barriers that impede their initiation (Jones et al., 2019). Delaying the conversation about designing an advance care plan can ultimately exclude the person with dementia because they are unable to participate anymore due to loss of cognitive capacity (Dening, 2015). van der Steen et al (2014) noted that the success of future advance care planning will ultimately be tailoring conversations to suit the needs of the person diagnosed, and incorporating all people who are included in their support network.

Alternatively, to the above processes in advance care planning, proxies have long been referenced in dementia literature (Beard, 2004a; Beard 2004b; Jones et al., 2019) in regards to various aspects of research and practice. Family members are the most likely people to act as proxies for people with dementia (Jones et al., 2019). However, it is a huge responsibility to place on care partners to determine what is best for someone with dementia (Jones et al., 2019, p. 828). In addition, Beard (2004a) has stated the use of proxies further stigmatizes people with dementia because it can be inferred that someone who requires assistance in expressing their wishes is unable to do so themselves. It also explains why there are very few instances of studies that represent the perspectives of those living with dementia.

Supplementary to the previous methods is the concept of shared decision-making. This could help incorporate people living with dementia in the process of carrying out their wishes for the future (Groen-van de Ven et al., 2018). The major barrier to this sentiment was the stigma associated with cognitive conditions, leading to the capacity of individuals with dementia being questioned. Legal capacity, competency, and ability to consent make up a large portion of the literature (Fetherstonhaugh et al., 2013). It is important to acknowledge that people with dementia expressed the desire to be involved in decision making, however they are often not given the opportunity (Fetherstonhaugh et al., 2013).

Some of the barriers to shared decision making aside from consent and capacity included facilitation, different preferences, and organizational barriers (Groen-van de Ven et al., 2018). It is important then that people living with dementia have strong support around them, including formal and family care partners, so that they are encouraged to be involved in decision making, rather than relying on their care partners to take over (Groen-van de Ven et al., 2018). If end of life was brought up, it would be important to ask the participants of this study how they think about their future in regards to end of life. How do they picture their role? Who do they see being involved in the process (family, friends etc)? And why? As demonstrated, external factors (institutions, care partners) play a role in how people's wishes are upheld, and as such may influence how people with dementia think about their future.

Echoing the mantra of 'living well' with dementia coincided with living in the present (Groen-van de Ven et al., 2018). However, it is argued that: "Timing decisions rightly implies anticipating future problems" (Groen-van de Ven et al., 2018, p. 850) which contradicts the ability to solely live in the present. Therefore, it is important to incorporate both the care partners wishes to address future plans, and the person living with dementia's wishes to live in the present (Groen-van de Ven et al., 2018).

The study done by Fetherstonhaugh et al (2013) was a valuable piece of literature because it contained the experiences of people living with dementia, and their perspectives on decision making. There were six participants in this study, all living in the community with a time since diagnosis ranging from 1.5-16 years (Fetherstonhaugh et al., 2013). The authors identified three main themes from their study that included: subtle support versus taking over, hanging on versus letting go, and being central versus being marginalised or excluded (Fetherstonhaugh et al., 2013). Participants recognized the progressive nature of their condition, and the increased likelihood of support but wanted to remain a part of making decisions with the support of care partners (Fetherstonhaugh et al., 2013). Participants were found to have an understanding of what their diagnosis could potentially mean for them in the future, but wanted others to ask them their perspectives (Fetherstonhaugh et al., 2013). One participant echoed this by expressing that he disliked when: “People talk about me, around me, but don't talk to me” (Fetherstonhaugh et al., 2013, p. 148). Fetherstonhaugh et al (2013) stated: “Autonomous individuals make choices and decisions about their own lives, and have the right to have those choices respected by others” (p. 143).

Supporting their autonomy by involving them in decisions, and respecting what they have decided made people with dementia feel respected, and helped them cope with their condition (Fetherstonhaugh et al., 2013). Finally: “the true essence of decision making for people with dementia, as one participant said, is feeling that “I am still here!” (Fetherstonhaugh et al., 2013, p. 146). Being an active participant in one's own care means individuals have the right to express their wishes and have them upheld. Sharing how they think about their future would identify the most important areas that people could support them in, and help facilitate their participation.

In addition to traditional advance care planning meant for use in medical or legal decision making, not as much has been identified that examined how people living with dementia are involved in daily decisions (Menne & Whitlatch, 2007 p. 811). This paper does not seek to argue whether a palliative approach to care is appropriate or not for people living with dementia, but instead focused on the processes available to people living with dementia that may be utilized to act on their perceptions of the future. If people with dementia discuss medical, end of life, or every day decisions, this review would prepare the researcher with the foundation to understanding the most common ways in which people living with dementia are able to participate in the process. Furthermore, it would enable the researcher to ask more critical questions relating to how they perceive their involvement, and what factors (family, support networks, institutions etc.) affect their perceptions.

The majority of research funding is directed towards varying pharmacological research initiatives that aim to treat symptoms or cure dementia (Kydd & Sharp, 2016). This research aims to refocus the attention back onto the person living with the dementia, in contrast to the amount of attention that has been focused on medical advancement. While appropriate, and important areas of study to eradicate the condition or make it less common, there is still an underlying assumption with biomedical approaches that people diagnosed with dementia need help, and less focus on people with dementia needing support.

Conversations about planning for one’s future could lead to conversations they have or will have with family, care partners or medical professionals about death or end of life. Therefore, it was important to recognize that this could be a part of planning for a future for people living with dementia, and address some of the literature surrounding perceptions of death and dying for people living with dementia. It has been found that the topic of death and dying from the perspective of older adults is seldom studied, even more so for those who have multiple chronic conditions (Clarke et al , 2012). Clarke et al. (2012) conducted a study with 29 participants and three themes surrounding death were identified: death as pervasive and inevitable, hopes and fears about their own death, and end of life plans.

Firstly, there was a recognition among the vast majority of participants who had recognized death as inevitable through experiences with death in their immediate circle, and accepted that it was going to be part of everyone’s life at some point (i.e. friends, family) (Clarke et al., 2012). Although there was a recognition of death and dying, some participants met the conversation with humor and acceptance whereas others were more fearful or felt unready for end of life (Clarke et al., 2012).

Secondly, participants addressed hopes and fears about death and dying (Clarke et al., 2012). Half of the participants feared a prolonged death or requiring institutionalization—for many of the men in the study they feared increasing dependency and loss of autonomy—and a third of participants feared they would be a burden to others, and an unwarranted drain on public resources (Clarke et al., 2012). Lastly, the authors addressed the theme of planning for death (Clarke et al., 2012). Reasons behind planning for death included: ensuring there was little burden on their family, making autonomous decisions for themselves and remaining in control, and intervention when there was a plausible decrease in quality of life (Clarke et al., 2012).

Some of the participants also discussed barriers to planning for end of life that included dealing with family relationships, and lack of knowledge and resources (Clarke et al., 2012). The interesting part of this study was that, much like the endeavor of this research, their study was not intended to revolve around end of life, but rather sought to determine the experiences of people living with chronic conditions (Clarke et al., 2012). An interesting quote from the authors read:

> Clearly, we had internalised assumptions about the taboo nature of death and dying by not even considering that it warranted attention in our interviews. Thankfully, our participants felt comfortable enough to disregard any uneasiness we might have unwittingly displayed or our lack of forethought about the importance of mortality to their experience of multiple chronic conditions… (Clarke et al., 2012, p. 14).

This study was important to consider in this review because it was from the perspectives of those living with a chronic condition; and perceptions was what this research was looking to uncover. Although this research did not ask direct questions about advance care plans, decision making, or end of life, it was about the future of those living with dementia. Dementia cannot be cured, so it was possible that the participants had thought about these topics.

Too often people fear asking difficult questions that may upset people or be untimely. Especially for people with dementia, researchers have echoed that their participation in research is often avoided for fear that it may not be of benefit, or harm them (Beard, 2004b). This quote raised an important awareness that: “When we are receptive to both listening to and valuing what people living with AD have to tell us, we will be well on the way to affording them the space necessary for a visible and credible advocacy role” (Beard, 2004b, p. 426).

To conclude, in contrast to terms such as proxies or shared decision makers presented in this section of literature, in Ontario the term substitute decision maker is used. A substitute decision maker is required when a person is no longer cognitively capable to make medical decisions (Speak up Ontario, 2020). There are different categories that outline who would be an individual’s substitute decision maker and they can be found in the Ontario Health Care Consent Act (Speak Up Ontario, 2020). Everyone in Ontario has a substitute decision maker—most often a close relative— regardless of whether they have appointed one in advance or not (Speak up Ontario, 2020). This section of literature has described the ways that perceptions of the future could be influenced by conversations about death and dying. It was therefore important to acknowledge some of the literature surrounding these topics; especially the studies that emphasized the perspectives of those living with dementia.

Chapter 4: Methodology

4.1 Introduction

This research addressed an important gap in dementia literature. While there have been studies that addressed all of the topics examined in the literature review, these studies often focussed on specific experiences or topics in isolation of other circumstances and experiences of people with dementia. In addition, there were very few studies that reflected the experiences of people living with dementia specifically without also adding care partner perspectives. My research explored the various experiences of people with dementia within the context of how they perceived their future.

There are many factors that may affect the way people think about their future such as receiving a diagnosis, coping, relationships, and stigma. The topics addressed in the literature review provided important context for better understanding how people with dementia could think about the future. Based on the data, theoretical implications were developed that exemplified the most important aspects of thinking about a future after being diagnosed with dementia.

As a researcher I recognize the stigmatization of people with dementia has had serious consequences. It has meant that their perceptions have not been taken seriously out of fear that their condition has impaired their ability to accurately depict or communicate their experiences. For that reason, I am using social citizenship as a lens to view this research. It was the reason for designing this research to rely on the experiences of people living with dementia and shaped how I interpreted and viewed their experiences. By developing theoretical implications based on their perceptions alone, it will validate the importance of their experiences and ultimately their ability to share those with us.

Biographical disruption was an acknowledgment that people do not become new people with a diagnosis of dementia; just an aspect of them has changed. Their biographies will undoubtedly play a part in how they process their diagnosis and continue to cope with it into the future. Biographical disruption has aided in the development of my methodology. Particularly, it informed the structure of my focus group sessions as a way to get participants to tell me the story of themselves living with a diagnosis of dementia. I wanted to learn about their entire journey before and after being diagnosed, not just aspects of their condition. This allowed me to delve into deeper meanings behind their perceptions.

4.2 Research Design

The experiences and knowledge of people living with dementia guided this research, and provided insights into how their conditions have affected them. Focus group interviews were guided by the topics discussed within the literature review, but questions remained open-ended to elicit conversation about their perceptions and thoughts about their futures. (For focus group guides see Appendix D). Various methodologies were considered when designing this research. At first, I had considered participatory action research because it was consistent with the ideologies surrounding social citizenship and viewing those with dementia as capable of creating meaning within their lives and possessing the ability to respond to and shape circumstances (Bartlett & O’Connor, 2010). However, because this study was an area of research that was missing from dementia literature I felt that it was necessary that it be guided by some sort of structure (i.e. that of taking some themes such as receiving a diagnosis, coping, relationships and stigma) and using that to create focus group guides. I had also considered later forms of grounded theory, but Charmaz’s (2014) constructivist grounded theory gave place for flexibility of research design, relationship to participants and social context. This flexibility was important when designing a study that addressed gaps in literature surrounding perceptions of the future and the value of their social lives in shaping those perceptions. In addition, given that there has been little in the literature about how people living with dementia think about their futures, and a dearth of theory related to this, developing a new theory through the use of constructivist grounded theory was an appropriate methodology.

Additionally, in Steeman et al.'s (2006) review of qualitative studies focusing on living with early dementia, grounded theory was found to be the prominent approach by researchers, and as a result, I chose grounded theory to structure this research as well. This study utilized biographical disruption and social citizenship as interpretive frameworks to situate how factors such as receiving a diagnosis, coping, relationships and stigma could impact how they think about the future, and act on those perceptions. Grounded theory, as explained by Charmaz (2014), allows the researcher to see things from the perspective of the participants. Constructivist grounded theory, as conceptualized by Charmaz (2014), provided guidance to the researcher on understanding the social world, not only focusing on what participants say, but also attempting to understand why. This is an important component of this methodology that is suited for exploring the thoughts and experiences of people living with dementia. Moreover, grounded theory is flexible, and Charmaz (2014) suggested the best studies follow a methodology but allow for reinterpretation of research questions if the data collection leads the researcher in a different direction. In my study, constructivist grounded theory enabled me to pay attention not only to what people discussed, but also to understanding what factors (e.g., relationships, stigma, coping) influenced people's perceptions of the future. The literature presented is the foundation for understanding some of the challenges people are faced with, and allowed me to ask more critical and in-depth questions. Ultimately, the goal was to have the participants inform me of the most important areas to be addressed.

4.3 Recruitment/Participants

Five participants were recruited through the Center for Education and Research on Aging & Health (CERAH), Dementia Café: A Place to Belong, and the North West Dementia Working Group. I am involved in all of these groups, and thus I approached people in person with a recruitment script (see Appendix F) and letter of information and consent (see Appendix G) to ask if they would consider being a part of this research. I was in the vicinity to answer questions, and all participants had other opportunities to interact with me for those who took the letter home with them to read over again. One person signed on the spot, and the other four signed consent forms before the first focus group took place.

Originally, I had set out to recruit four to six participants for this study to participate in three to four focus groups. In total, five participants agreed to participate and four focus groups were completed. Unfortunately, only four participants completed all four focus groups. One participant was only able to attend one session because of subsequent COVID-19 restrictions. Further explanation will follow in section 4.7. Although gender was not a focus of this study, it is prudent to mention that four participants were male and one was female.

All participants lived independently in their own homes within the city. They had the means to travel to the Centre for Education and Research on Aging & Health (CERAH) where focus groups took place. As well, participants gave their own written consent, and were reminded verbally at the beginning of each focus group (see Appendix H for verbal consent script). Additionally, the phone number for the Alzheimer Society was given to them at the focus groups in case they experienced emotional upset and needed to seek counselling. The number of participants was chosen so there were enough people to engage in conversations with each other, but not so many that they felt they could not talk in depth without allowing another person the time to speak.

The groups I recruited from had a focus on dementia advocacy, and all of these participants were arguably motivated to speak out about their experiences in the hopes that they could make a difference for other people living with dementia. This required consideration when interpreting the findings of this study. Since people living with dementia are often silenced, it is important to remember that the individuals who participated in this study were in a position of privilege where they were supported and encouraged to speak out about their condition, and were well connected in the community as a result. However, their advocacy work has also allowed them to see the negative experiences of others in their mission to seek change where other people living with dementia are excluded. This is likely what fuelled their passion for sharing their experiences.

Participants for this study were selected according to the following inclusion criteria:

1. Must be able to give informed, and ongoing consent to participate in the research
2. Be living in their own place of residence in the city of Thunder Bay, ON
3. Must have been formally diagnosed with dementia
4. More than 1-year post diagnosis, and less than 12 years
5. Have the resources and ability to travel to CERAH for the focus group interviews

One to twelve years post diagnosis was chosen to ensure people had time to process their diagnosis, and think about their future. People are known to CERAH that have been diagnosed with dementia for more than twelve years, but in some cases, questions arise about the life-limiting nature of the diagnosis after years of living well without significant progression. As such, I decided to limit the participants to twelve years post-diagnosis. Because 90-98% of dementia cases are diagnosed after the age of 65 (Alzheimer Society of Ontario, 2012), it was assumed that this research would incorporate seniors 65 years or older; however, I did not ask participants to disclose their ages. Individuals were able to give their own informed consent to participate in this research.

Furthermore, the demographic characteristics of participants beyond the above criteria were not the main focus of this research. Although gender, ethnicity, health and socioeconomic status may contribute to conceptualizing a future with dementia, it wass not the focus of this research. However, it was important to acknowledge the basic demographics of my participants so that future research could look into more specific categories (age, ethnicity, gender, socioeconomic status) and how those could potentially impact people's perceptions of the future living with dementia. This research aimed to more broadly identify the most important themes related specifically to dementia and the future, particularly in light of the significant gaps in the literature.

Description of Participants

Sophia lives independently in her own home with her husband. Sophia has had past experience with close family who were diagnosed with dementia. She is also engaged in various social and recreational activities within the city. Sophia is very active in advocating for those living with dementia. She has been diagnosed for less than 10 years.

Ben lives independently in his own home with his wife. Ben had no previous experience with dementia, but did have experience with a close family member who had a different chronic condition. Ben participates in community activities, but wants to spend more time engaging with those living with dementia. He has been diagnosed for less than 12 years.

Thomas lives independently in his own home with his wife. Thomas has past experience with a close family member who had lived with dementia. Thomas enjoys participating in various social and recreational activities in the community. Thomas is also very active advocating for those living with dementia. He has been diagnosed for less than 10 years.

Robert lives independently in his own home with his wife. Robert has past experience with a close family member who had lived with dementia. Robert enjoys various hobbies, and being engaged in multiple different community activities. He has been diagnosed for less than 10 years.

Joseph lives independently in his own home with his wife. Joseph did not have past experience with dementia, and did not identify any specific experience with other chronic conditions. He has been diagnosed for less than 10 years.

4.4 Consent

Safety and respect for all involved in this research was critical. It was my responsibility as the researcher to watch for signs of discomfort and end interviews should people become distressed. Information to obtain support services immediate and ongoing (from the Alzheimer Society of Thunder Bay) was available during all focus groups. CERAH, Dementia Café: A Place to Belong, and the North West Dementia Working group all have partnerships with the Alzheimer Society of Thunder Bay, and their representatives are actively engaged. Even though it was not needed, those partnerships would have aided in a quick referral. The written consent form was informed by Creswell and Poth (2018) as well as the Tri Council Policy Statement 2 and contained:

- participants' ability to withdraw at any time
- purpose of the study
- data collection strategies
- measures taken to ensure confidentiality
- risks/benefits of the research, and
- the signature of the participant/researcher

Although written consent was obtained prior to the first focus group, ensuring at the beginning of each focus group participants understood their consent was ongoing, and could be withdrawn at any point in time was critical (Dewing, 2008). A verbal script was read to participants at the beginning of each focus group that detailed the purpose of the study again, that the study was voluntary, that withdrawal from the study would not impact their participation in the organizations they were recruited from, and that conversations were audio recorded. Participants were read the verbal script at the beginning of each focus group and were asked if they had any questions about the study before beginning. All expressed their consent to continue participating at each focus group. In addition, I reminded participants that the nature of focus groups meant that information may not be kept confidential, but I reminded everyone that the conversations we have should not be discussed with others outside of the group.

4.5 Data Collection

This research relied on focus groups as a means of data collection. This method of data collection was chosen with thoughtful consideration of participants and how to gather information with the most depth. All of the research questions focussed on their experiences living with dementia, to compare and contrast the experiences amongst the participants. This method proved to be quite successful. Participants echoed the importance of being engaged with others that had the same condition, so that the difficulties they experienced did not make them feel so isolated. The data gathered showed that this particular group of individuals felt empowered talking about their condition. As a result, the conversations we had during each session were not unidirectional. After I asked questions, participants spoke about their experiences. Soon participants were talking among themselves, offering up sentiments to each other and words of encouragement that they were not alone in their experiences. It was moving to see the compassion and camaraderie they had for each other. Dementia was not something that made them different, but was what made them the same.

Originally, I had proposed to use videos to initiate conversations, but I did not use them. However, careful consideration was paid to how these aids may have influenced topics of conversations. If used, these videos were meant to stimulate conversation based on their interpretation of the video (see Appendix C for proposed visual aids and descriptions) in instances where participants were struggling with conversation. After conducting the initial focus group, it was apparent that participants had plenty of their own experiences to share, and they were unintentionally answering subsequent questions that were in the focus group guide before I had a chance to ask them. This gave me the confidence to leave the videos out, and let them speak and answer the questions without influencing what direction they were intending to take during conversations.

This research utilized focus groups as a self-contained method for primary data collection (Morgan, 1997a, p. 2). The choice for focus groups was made for its strength in producing data through interaction of participants (Morgan, 1997a). Charmaz's (2014) grounded theory is an inductive process, and utilizes participants as co-constructors of knowledge; a crucial component to ensure their experiences are exemplified in the resulting theoretical implications. Movement beyond the emerging themes from these focus groups was also a part of this grounded theory research. A layered approach to data analysis took this a step further and revealed what had influenced participants' perceptions about the future. The interaction among participants provided richer data than would have been possible in one-on-one interviews, and allowed me to derive the meaning behind themes identified during focus groups.

The organizations and groups that these participants were recruited from were all places that I worked or volunteered for. I was employed at the Centre for Education and Research on Aging & Health (CERAH) as a graduate assistant from September of 2018 until April of 2020. CERAH also supports the North West Dementia Working Group by providing a space for meetings and helps with facilitation, which was an important function of my work at CERAH. As an employee at CERAH, my interaction with participants included conferences, meetings, and public speaking engagements. The Dementia Café: A Place to Belong is held at Urban Abbey and is a joint initiative run by CERAH. My supervisor Dr. Elaine Wiersma is the founder of this Café. Not only was I known to these participants, but they knew each other as well; rapport was built before focus groups started.

To minimize the impact of the researcher on discussions, which has been noted as a weakness of focus groups (Morgan, 1997b), guidance was limited to using broad themes, with open ended questions that allowed participants to interpret them independently and amongst each other. Because I had worked in the organizations where these participants were recruited from, there was rapport from the beginning. This was an important aspect to this project, as speaking about experiences living with a chronic condition could bring up sensitive topics; arguably harder to speak about in front of a stranger.

Focus group discussions included questions about receiving a diagnosis, coping, relationships, stigma and the future and were organized into *the past*, *the present* and *the future*. This was done to determine not only what the most important aspects of people's future were after receiving a diagnosis, but what their experiences had been prior to, during and after diagnosis that may have affected those perceptions. The focus group guide can be found in Appendix D. Lastly, the flexible nature of constructivist grounded theory allowed adjustment of focus group sessions, specifically the addition of a member checking focus group. After three focus groups were completed, clear themes emerged and were consistently being spoken of. Data were then coded, and more specific questions beyond standard open-ended questions about themes were added (see Appendix I). This member checking focus group proved to be crucial to ensuring that the saturation that had been witnessed was accurate. It also enabled more in-depth analysis of people's perceptions by amending the focus group guide to include tailored questions that arose after the initial focus groups had been coded. This was crucial when collecting data about people's experiences which required in-depth responses and explanation.

4.6 Data Analysis

The first focus group was audio recorded with recorders provided by CERAH. The remaining three focus groups had to be amended through Lakehead's Research Ethics Board to transition to Zoom after COVID-19 prevented campus access. All focus group recordings were transcribed after completion. Immediate reflection after focus groups, and again upon completion of transcription was important to the initial identification of themes. Memoing was another important component to data analysis that helped ensure credibility (Creswell & Poth, 2018). Memoing was the process utilized to document ideas and emerging themes during and after focus groups, but also into data analysis. These memos aided in constant comparative analysis, where perceptions and experiences were constantly compared across the focus groups and across participants. Focus groups were analyzed separately, and then together to compare and contrast what was said in each focus group, and amongst all of them.

The meaning behind the perspectives of participants was identified because of the depth of conversation. This process was aided by the participants’ engagement with each other’s stories, where they were comparing and contrasting their experiences living with dementia. The relationships they had with each other, and the researcher aided in this comfortability. Memoing was organized by what Charmaz (2014) has called a methodological journal, which consisted of memos, and various process notes on emerging themes throughout the process of data collection and analysis. This journal encouraged reflexivity and intricate connections among the participants experiences within and throughout all focus groups. As well, it was used to document the experiences of the researcher conducting these focus groups. This was helpful in identifying struggles, mindset and the potential for those to produce undue influence on participants.

Furthermore, initial coding consisted of InVivo codes that reflected the language participants used to describe their experiences (Saldaña, 2013a, p. 61). This was an important step because it was crucial that the integrity of participants’ experiences was reflected in the use of their words, as opposed to the researcher’s, as much as possible. This however did pose challenges to subsequent coding and will be discussed within the personal reflections section.

Subsequently, focussed coding was used to identify major themes within the data (Saldaña, 2013b). Incorporating ongoing ‘member checking’ ensured the research addressed what was important to the target population (Creswell & Poth, 2018). This was accomplished by continually asking for clarification during focus groups when needed. As well, the use of a final member-checking focus group enabled broader themes derived from individual experiences to be confirmed. This ensured that data, and the subsequent theoretical implications, were reflective of their experiences and enhanced the trustworthiness of this study.

Saturation was reached after the first three focus groups. The use of a methodological journal allowed me to identify recurring themes, and recognize that saturation had been reached. As a result, I decided to code the initial three sessions and develop more in-depth questions to illuminate their perceptions of the future even more so than the original open-ended questions had originally intended to address.

4.7 COVID 19 Implications to Data Collection

I completed my first focus group on March 9th, 2020. Originally, I had planned to continue each group every Monday thereafter. On March 16th all participants except one chose not to attend the session because of the recent announcement of COVID-19 outbreaks. From that point on I had to decide about the rest of my sessions. The next day, Lakehead University announced that no more gatherings should be held on campus. I felt that it was integral to my research that I maintain the use of focus groups, so transitioning to one-on-one phone calls was a last resort. Between conference calls and Zoom, I believed that Zoom would facilitate the most amount of interaction among my participants.

I assumed that transitioning to Zoom was not going to work out very well. I was unsure of how many participants would be able to use the platform, and if they did manage to use it, barriers such as hearing might greatly affect the connection and interaction that was so important to my data collection. However, all participants except one were able to get on Zoom with simple instructions. One participant unfortunately was unable to participate in the remaining focus groups because he was unable to get Zoom to work on his computer. I phoned him numerous times over approximately two weeks trying to help him before he expressed that he felt that it was just not going to work. On April 3rd, and 10th, 2020, I was able to conduct two more focus groups with the remaining four participants; bringing the total to three sessions. However, on April 3rd, I unfortunately had one participant cancel because they had lost their internet that day. There were definitely challenges to using Zoom to conduct focus groups. First, I was not confident in my ability to facilitate discussions online. This was my first-time conducting interviews of any kind, and after my first focus group, I realized it was a challenge to moderate, take notes, and be actively engaged with my participants. They had so much to share at the first session that I quickly realized the importance of subtle social cues. In observing some participants, I could gauge when they wanted to talk; making eye contact with them gave them the go ahead to jump in and contribute. Subtle interactions such as those were certainly more of a challenge for me on Zoom. I found using Zoom was overwhelming in the beginning and I had to adjust my tactics.

In addition to the struggles that I was trying to mitigate, there were some obvious struggles for my participants as well. For example, hearing was a challenge for some. Some people’s audio cut out if another participant would say ‘ok’ or ‘hmm’ in affirmation or agreement to each other. Other times it was simply that they did not have the volume up high enough. Similarly, eye contact was an issue. I was no longer able to just ask a question and let them respond. They would wait in silence until one would ask ‘are you talking to me?’ I had to adapt and start asking questions directly to each individual. This did impact the amount that the participants interacted with each other in comparison to the first session we had in person, but admittedly it was not detrimental.

For what I lost in data during the two focus groups that I held online I made up for by amending my final focus group guide. I did in fact need a fourth session. Originally, I had created a guide for the final session that had two blanket questions that asked if a theme I had identified from the first three sessions was accurate to their experiences. After consideration, I decided to code all the data that I had collected thus far and develop more in-depth questions for my last focus group that made my data more rigorous than the previous member checking questions. The member checking focus group functioned to affirm the themes I had generated from previous focus groups. In addition, I asked supplementary questions about sub-themes I noticed such as independence and how others can support it, other people’s perceptions of their abilities, if they thought about the future differently than those not diagnosed with dementia, and lastly, the importance of being around others with dementia.

This member checking focus group affirmed the importance of support networks in their ability to accept their diagnosis of dementia. Participants noted the importance of their families, friends, doctors, others with dementia and organizations or supports that allowed them to remain both socially and physically active. This final session was held on June 12th, 2020.

4.9 Personal Reflections

Data Analysis

After the first round of coding I was overwhelmed by the way I had coded my data. By using participant language only some themes such as acceptance or support were obvious. Whereas stories or anecdotes that, when examined broadly were relevant, seemed less so with my initial coding strategy. I started to wonder if I had coded my data correctly, and whether or not I should start the process over. I eventually decided that the answer was to try coding again but on paper. My inexperience using NVivo was contributing to my frustration and doing things on paper was much easier. I was starting to believe that NVivo was not necessarily built to capture my data correctly, but in fact NVivo is just a tool and I did not know how to manipulate it to suit my needs. The next round I coded for context, rather than taking a line by line approach. From there, it was much easier to capture the meanings behind what participants where saying.

Coding emphasized the importance of people’s words. I was very focussed at the beginning to only code with participant language because I wanted to ensure that these findings were reflective of their experiences. However, Charmaz (2014) recognized that all researchers have bias; it is being aware of it that matters most. In addition, Charmaz (2014) emphasized the importance of language in constructivist grounded theory because the words we use give us insight into meaning. Constructivist grounded theorists encourage their participants to share the meanings behind the stories and experiences they share with us (Charmaz, 2014). Reminding myself of these fundamental elements of constructivist grounded theory enabled me to code my data more efficiently. I started to gain confidence interpreting my participants stories, and realizing that my final focus group session was a way that I could ensure that my interpretations were accurate.

Researcher Positionality

To begin, it is important that I situate myself within this research. When I was in high school, I was first introduced to palliative care. My great grandmother had fallen and broken her hip which required immediate surgery that the doctors did not believe she had a good chance of making it through due to her underlying health conditions. The surgery was a success; however, our sense of relief soon faded as her post surgery complications were diagnosed as stage four cancer. Neither surgery nor chemotherapy was an option for her and she was placed in a palliative unit. Shortly after this my other grandmother ended up three doors down from her after going to the hospital not feeling well. She too was diagnosed with stage four cancer and neither surgery nor chemotherapy was a curative option for her either. My experience spending time with each of them in the hospital is not a moment in time I like to remember. I felt as though I was looking at different people lying in those hospital beds. My fond memories of spending time with them were being replaced by images of them suffering and ultimately saying our goodbyes. Both of them were in the palliative unit for only a short amount of time before they passed.

After the death of my two grandmothers, there was a void. For my great grandfather it was probably the most apparent. He struggled a lot while his wife was in the hospital and when she passed, his difficulty only worsened. As a family, we had not noticed that my great grandmother covered a lot of his struggles and when she was gone, they became glaringly obvious. Her physical health was not good, but she ran a tight ship. She made sure he did all his farm chores, reminded him of what he was cooking, and where he put the tractor keys. But this was not just her way of running the household. He was struggling with his memory and her death only made it more apparent. He was soon diagnosed with dementia, and his daughter became his primary care partner.

The topics of this research were not chosen at random. They have a personal meaning to me; however, the details have evolved over time. In my undergraduate degree, I completed an interdisciplinary studies program and focused on biology and psychology and completed my honours project on palliative care. I wanted to understand why. Why did my grandfather develop dementia? And, why had I never heard of palliative care in the numerous health inspired topics throughout school? Fundamentally I accomplished what I wanted. We do not know why the brain degenerates and talking about death is taboo. This did not make me feel better about either experience and I wanted to know more. You could take a quote from my application to this masters' program which I believe exemplifies how I felt about dementia.

> *"…as powerful as our brains can be, they can also show signs of fragility. In what seemed like a short period of time, the disease completely changed what had once defined the person that it had taken a hold of. Not only did it affect memory, but emotion, and the overall ability of the person to function as they once did"* (Lakehead Letter of Intent, 2018).

My memories of my grandparents at that time were still overshadowed by the way things had ended, but as I have realized, it was more so how I interpreted them. After starting my masters, I was quickly met with opportunities to be around people living with dementia, and more opportunities to learn about palliative care than I could have imagined. No one at the Centre for Education and Research on Aging & Health, nor the members of my committee were afraid to talk about dementia or palliative care. I realized there was more than what I had been exposed to. Dementia was more than biology, and palliative care was more than the final days. After initially identifying a tension between palliative care and dementia, I decided my main focus was going to be on people living with dementia and I would let them tell me about their futures. I ended up taking a more sociological approach to my research, and pursued a study that let the real experts talk; those diagnosed with the condition. I let them tell me about living with dementia and this included the positives which I hadn't been able to see before.

Initially wanting to ask them specifically about palliative care and end of life, I then changed my mind. In learning how disempowered this population can be, and how our assumptions of their abilities—including telling us what they want was a problem—I chose to ask them about their futures instead. These individuals do have futures despite being diagnosed with a life limiting condition, and how they think about their futures was something unstudied. Maybe they would bring up palliative care or end of life, or maybe they would not. I decided to prepare myself the best I could. I studied the dementia literature and took the most prevalent topics of research: diagnosis, coping/adapting, relationships and stigma and used those as a guide to what I needed to educate myself on. Although I recognized the tensions between people diagnosed with dementia and those who believed that they should assume a palliative approach to care I included it in the literature. I anticipated that asking individuals about their future may bring about conversations of death or end of life. I did not want to shy away from those conversations with participants because I was ill informed about that aspect of healthcare; to me, this would only further reinforce that death was a taboo topic.

The research about living well with dementia informed my work. However, my research aimed to be different because I wanted to know what they thought about their futures. In discussion with my supervisor, this was different because *thoughts precede action*. In addition, it aimed to take into consideration the deeper meanings behind each individuals' journey living with dementia. This was not to ignore what these people were *doing*, but in talking about what they were doing, the things they have done, and the things they want to do I was hoping to uncover a mindset or thought process that led them to those actions. Therefore, I framed my focus groups, unbeknownst to my participants, as *the past*, *the present* and *the future* and we talked. I do not know what other people's interpretations of my research will be, but to me it was a success. It uncovered buried memories of my grandfather that made me remember that he did not leave this earth as a shell of what he once was. My ability to see him was just impaired. And, that my grandmothers' final days will not ever overshadow the lessons they taught me and fond memories I have of them. I am grateful I had the opportunity to say goodbye.

Chapter 5: Findings

After much reflection, I questioned why I asked my participants about their future. Throughout the focus groups, I had critically reflected on how participants' perceptions of the future were being expressed if they were not explicitly using the phrase *my future* when answering questions. The future truly was anything that had not yet happened. In addition, the meaning behind their perceptions of the future required more in-depth analysis to interpret how they were speaking about aspects of their lives that they were foreshadowing. Their past and the present were also crucial to who they were, and how they were experiencing their condition. Having a future is not what will make these individuals seen as worthy of our attention, but rather our complete examination of the lives they have lived and continue to live.

My focus groups (FGs) were designed as *the past (FG #1)*, *the present (FG #2)*, *the future (FG #3)* to see how these periods of time in isolation may have influenced their perceptions of the future living with dementia. However, I found participants were unable to talk about their past without mentioning the present, and the future without talking about their past and so on. The past, the present and the future are periods of time, but I had not identified that my study was going to be specifically about time. Time is traditionally quantifiable in basic units of measure such as minutes, days, months and years. I believe that is how I, and others are most likely to conceptualize time as well. To these participants, clear borders were blurred and the past had been brought into their present and their future. Not all of their past was left behind, and not all of their future had been thought about. All of these periods of their lives had impacted their perceptions of the future, and were continuing to do so. To solely divide the data into those distinct measures of time did not illuminate their experiences, as I have learned that there are different ways to conceptualize time. Jowsey's (2016) review identified four different temporal structures of time including biographical and past-present-future time which became important to address in the discussion of the findings.

Instead, I have allowed the quotes to fit into broader themes and utilized tags at the end to show whether it came from the focus group about the past, present or future. The stories that these themes were derived from gave insight into how these participants think about their future, and what had influenced those perceptions. The readers will be able to see that themes are presented in various tenses, and show an evolution of their perceptions. The future is not a quantifiable measure of time, but more aptly thought about conceptually by examining their perceptions. These individuals' perceptions about their diagnosis have been, are being, and will continue to be shaped as they continue living with dementia. Quotes have been labelled by session, denoted by the tag within the bracket. This will allow the reader to explore how conversations about the past and present have influenced their perceptions of the future.

There were six key themes that emerged from the data capturing participants' perceptions about the future. The first theme, "Making the best of it", describes how participants focused on the positive aspects of life and of living with dementia, including "it could be worse", "accepting dementia", "learning from the past" and "using humour". The second theme "I'm still capable" described how participants wanted to be seen as cognitively capable and challenge the stigma associated with their condition. Third, "finding solidarity" meant that people living with dementia felt they belonged and were not alone when they engaged with others who also had dementia. The fourth theme "life is ahead of me" described how participants believed that there was a fulfilling life left to live. Sub themes of this included "carrying on", "staying socially engaged" and "charting a new path". The fifth theme, "The future is measured by pivotal moments" described how participants measured the future by what they were no longer able to participate in as a result of their cognitive decline. Lastly, “the future depends on relationships and family” described the importance of support from close relationships.

The first four themes of this research “making the best of it”, “I’m still capable”, “finding solidarity”, and “life is ahead of me” described the present future in their daily lives. The present future focussed on incorporating dementia into their lives in a way that facilitated their continued engagement in things they loved to do. The themes “the future is measured by pivotal moments” and “the future depends on relationships and family” described a more distant future. These two themes depicted how participants thought about living with dementia when it might significantly impact their lives by a loss of ability or cognitive decline. (See Figure 1 *The Future Living with Dementia*)

Figure 1

The Future Living with Dementia

5.1 Making the best of it

All participants discussed how they were making the best of their diagnosis, and the changes that dementia might bring. While many people might see dementia as a very negative diagnosis, participants described how they were able to see the positive benefits that dementia brought them, even if this was sometimes difficult. "Making the best of it" was demonstrated through four main themes: 1) it could be worse; 2) accepting dementia; 3) learning from the past and 4) using humour.

Sophia in particular expressed the importance of making the best of life's situations and her passion for sharing her experiences with others who have dementia so they too could make the best of their challenges. She stated: "Make the best of what you get. And I share – any time I can, I share my experience with anybody that asks me. I said 'No, stay positive. Don't let any little thing get to you.' You know?" (FG #3-The Future). She further echoed: "So, grab hold of it. You take charge. Don't let it run your life" (FG#3 The Future). Sophia's desire to advise others with dementia that they too could make the best of their diagnosis, and accept it showed that she had a positive outlook on her future. She wanted others to know that despite the challenges that a diagnosis of dementia could bring, their life was not over. Thomas also echoed: "I got to live with it and do the best I can" (FG#2 The Present).

These individuals were making the best of the challenges that their diagnosis brought, and continued to live their lives. Sophia commented on this and expressed how she has made the best of her diagnosis:

> I mean, God. I tell anybody that can – if they said 'Ah, poor you' I said 'No, not poor me. I got a ticket that says I can be a fool if I want.' [Laughs] I can do whatever I please.

> [Laughs]. I mean, come on, let's face it, you're only here once you may as well enjoy it. [Laughs]. But there are days I don't like it and I can't handle it and I go and I just have a good talk to myself. (FG#3 The Future)

The "ticket" she talked about is a card that she has in her wallet explaining that she has dementia, and this is used to show others when she might be having difficulty communicating or functioning. She acknowledged there could be struggles as a result of her diagnosis, but that she could still find enjoyment in life. Moreover, those hard days were something that they could overcome. Sentiments such as: "I just have a good talk to myself" or "This is not so bad" showed that these individuals believed strongly in having a positive mindset. Having a bad day did not mean their life was no longer fulfilling; they were making the best of the challenges they faced.

5.1.1 It could be worse

Throughout the focus groups, participants made comments comparing dementia to other illnesses. Participants did not perceive their condition to be as severe as other adversities people could live with. Sophia gave a few examples of what she believed to be more difficult than her diagnosis:

> So, you stay positive. And some days you have — I anyways, might have a day where I feel 'Shit, this stinks; I don't like it' you know, [laughs] but then I think 'Ah, I could have cancer. I could be curled up in a bed. I could be barfing my guts out. I could be in pain. This is not so bad. (FG#1 The Past)

Perceiving that their situation could be worse helped participants to put their lives into perspective and make the best of their diagnosis and the associated changes. They believed that dementia did not impede their ability to live fulfilled lives.

To these participants, their futures were more manageable than the futures of individuals who may be experiencing other types of illnesses. They accepted that their future may bring challenges, but they felt they had the power within themselves to overcome and push through those difficult times. Sophia also expressed how having Alzheimer's wasn't as bad as people might think:

> Like I said, it sounds stupid, but having Alzheimer's isn't as bad as people make it out to be. I mean, it's not great. There's days I hate it, but those are cut pretty short as soon as I grab hold of it. (FG#3 The Future)

She again acknowledged that there were difficult days, but that she took control of those days to make the best of her condition. Similarly, Ben talked about not getting upset about some of the difficulties that his diagnosis had forced him to deal with. This was exemplified in his quote: "And try, and not get mad at yourself or feel sad about yourself. I mean you're still alive" (FG#1 The Past). Ben expressed that he experienced some challenges as a result of dementia, but there were so many other things in his life that he enjoyed doing. Not being alive was something that could be worse than some of the challenges associated with dementia.

In addition, participants echoed the sentiment that they too did not want others to feel sorry for them because they were still living good lives. Sophia stated: "As I said, we're not sick, we're not — limping around and crawling or, you know" (FG#1 The Past). Participants described how they thought their situations could be worse. They continued to express sentiments of living good lives and moving past the challenges as a result of dementia.

5.1.2 “I Had to Accept What I Had to and Move Forward”: Accepting Dementia

Coming to accept a diagnosis of dementia was not a one-time occurrence; participants accepted their condition, but were continually choosing to accept their diagnosis and the changes that it could bring. Acceptance was a recurring theme throughout all focus group sessions, and was viewed by the participants as integral to living a fulfilled life. It meant they were aware of the challenges their condition could bring, but their positive mindset allowed them to feel empowered. For these individuals accepting their diagnosis allowed them to focus on what made them happy and live a fulfilled life.

Acceptance was an acknowledgment that they did have a future; their life had not ended with a diagnosis of dementia. Sophia stated: “But, I mean you’ve got to make light of this thing. You can't let it drag you down, you know” (FG#1 The Past). Sophia accepted that she had to live with dementia and it was not going to get the best of her. Furthermore, acceptance was not synonymous with indifference. Participants were well aware of the challenges that their condition brought or could bring about in the future. Choosing to accept their diagnosis meant that they chose a particular mindset of positivity. They chose, and continued to choose, not to let their difficulties prevent them from living a fulfilled life. Accepting their challenges and sentiments about moving forward such as “I had to accept what I had to and move forward” (Thomas, FG#1 The Past) and “You have to accept it at the beginning” (Ben, FG#1 The Past) demonstrated that these individuals believed they had a future.

Participants were asked for clarity about accepting their diagnosis during the first focus group. I had interpreted that they all expressed that they had accepted their condition, but were describing ways that it was still being reaffirmed. When I asked whether or not they believed that they had moved on since their diagnosis, they all stated that they had achieved acceptance. They remarked: “Oh, I moved on” (Sophia, The Past) and “…what am I going to do?” (Ben, The Past) which demonstrated they had accepted their diagnosis and were moving forward with life. Some struggled for a while in the beginning, but at that moment in time, all were in agreeance. However, acceptance appeared to be an active process as participants described actively making decisions to accept their diagnosis and have a positive attitude. Sophia stated: “…we’re in charge of how we feel about what happens” (FG#1 The Past). Having a positive mindset about dementia gave them control over it. They did not choose to be diagnosed with dementia, but they did choose to accept it.

Furthermore, the journey to acceptance was achieved differently among participants by utilizing different strategies. For example, the following quote demonstrated how Thomas and his wife used counselling to help him cope with his diagnosis of dementia. He stated:

> I come to realize that I had to accept what I had, yeah. It took a while. And so, once a month and then I think in year two and possibly into year three I didn’t need it anymore. We didn’t need it anymore. And I've been in remission since then. (FG#1 The Past)

Counselling was one of the ways that Thomas coped with his diagnosis and eventually it helped him accept it. The development of strategies to cope was crucial to how these individuals were able to accept their diagnosis, and for Thomas it included some counselling.

Moreover, participants' past experiences impacted how they came to accept their diagnosis of dementia. Sophia brought up her mother's experiences with dementia many times throughout focus group sessions. She spoke fondly of her mother, and expressed admiration for the intelligent, hard working woman that raised her. However, Sophia remarked that dementia did not discriminate between people, that there was no prevention for dementia, but that one could always choose to accept it.

> …nobody knew what to do with them back then. But, I mean, so it doesn't matter how smart you are or whatever, when the big guy says 'This is your gift' you take it, say 'Thank you' and get out [laughs]. Yeah, so … so that's seen a lot of it, seeing how you can deal with it and how you – like you know. So, I say it's up to the person that has it, how they're going to handle it. And I've seen so much of it that this is the way I want to handle it. (FG#3 The Future)

Sophia had seen what living with dementia was like for her mother, and chose to accept her condition and move forward with her life because of the examples of others.

Participants' discussions of their acceptance of their diagnosis implies a future. Acceptance of their diagnosis meant that there was a movement forward. Although the words, *the future*, were not always explicitly stated in these quotes, they looked forward to being active in their own lives. That outlook meant that they still envisioned themselves living a meaningful life into the future. These individuals also recognized that they may not have been able to control their rate of decline, but they could choose how to handle it; and they chose to continue living their lives and doing things they loved.

5.1.3 “I Think You Learn from What You See”: Learning from the Past

“Learning from the past” captures how participants learned strategies on how to accept their diagnosis from past experiences. Participants’ acceptance of their diagnosis of dementia came from past experiences with family and friends who had dementia and those who had other chronic conditions. Their experiences and interpretations of these situations in light of their diagnoses had given them resources upon which to draw to accept their diagnosis and the challenges that it posed.

Direct experience with the same condition was not necessary. Ben had told stories about an individual he was close to who had lived with a chronic condition other than dementia. His stories of him were of admiration for the strength and perseverance that he displayed despite the challenges that he encountered both in his personal and professional life. Ben described the continual determination of this person to keep going, and prove to people that he could do things on his own. After Ben shared this story, Sophia spoke up and said: “Well so he was a good example for you how to accept your Alzheimer's or dementia, whatever” (FG#1 The Past). To which Ben responded with affirmation: “That’s right, exactly. It’s there, accept it. He had to” (FG#1 The Past). Ben took this experience from his past and used it as inspiration to continue living a fulfilled life with his diagnosis of dementia. Similarly, Sophia had also learned from her past and shared her experience.

> I think you learn from what you see, like you know, what you’ve lived with or seen in your neighbours or … If you’ve seen it and been around it, I think it gives you an idea of what you can expect and how to live with it, and how you don’t want to live with it. Like, you know, like you don’t want to be sitting at home because we know now, stay social. (FG#1 The Past)

Sophia learned from other people living with dementia not only what to expect but how to handle it. She learned that staying social was important and knowing the challenges associated with one's condition, or dementia specifically, could provide insight into how they could live well with their diagnosis.

Only one participant did not have direct experience with dementia or another chronic condition. Although after discussion with everyone, Joseph made a connection to a past experience when he was younger about observing how older people "acted strangely". He described someone he knew that after having retired would still pack a lunch and go back to where he used to work. Although having never associated this man's actions with dementia, after listening to other participants' stories about their experiences with people living with dementia, he made this connection. He further referred to believing his grandfather had not "acted normally for some years. But I had never identified him with Alzheimer's" (FG#1 The Past). Other participants chimed in and stated that he may not have known if those individuals had dementia because "way back when though, they didn't know exactly what they were dealing with" or they "tried to hide it". This showed the importance of people's pasts and how influential they could be on an individual's perceptions of the future. Thinking about someone from their past who "acted strangely" carried a more negative connotation than Sophia's experience where she knew her mother had dementia and was able to critically reflect on her experience and learn from it. Participants' pasts had clearly influenced them and they drew upon those memories when asked about their own experiences living with dementia.

In addition to learning about what a diagnosis of dementia could mean for them and finding ways to cope, they had learned about the stigma of dementia that others in their past had experienced. Participants shared stories from their past about the stigmatization of people living with dementia and compared it with their present experiences. The below quote was a story that Robert told about an experience he had when he was younger. Robert described how he had misunderstood the memory difficulties his uncle was experiencing not realizing that he had an underlying condition.

> I was first exposed to dementia when my two uncles ended up in the seniors' home in [town 2]. And I would go to visit them. I'd say, 'Well [Uncle], how are you doing?' 'How in the hell should I know?' We thought that was funny at the time, but he was serious. He didn't know. And my other uncle said, 'Yeah. Well they get along pretty well together don't they? What's your name again?' (FG#1 The Past)

Now Robert realized this was something serious. Once Robert was told that his uncle had dementia, he viewed him differently. Robert had since reflected on this experience as an important lesson to not make assumptions about people; take the time to understand them. This shows how the experiences of others can shape people's perceptions. Not only did this experience shape how Robert viewed dementia presently, but it also demonstrated the power of learning from the experiences of those living with dementia that could be applied in the future.

Similarly, Sophia reflected on her past experience watching family members live with dementia, and believed that she was better off today than they were. She stated: "…today there's so much more to help people than there was back then, so we're very fortunate really because we have places to go, you know, and everything. It's just that stigma that's attached to it" (FG#1 The Past). Stigma was not just hiding the fact that one had dementia in fear of other people's judgement. Stigma was the lack of inclusion of those living with dementia. Sophia felt that there had been an improvement compared to those in her past who lived with dementia. Although she recognized that stigma was a barrier to accessing help in the past, presently she felt there was much more for those living with dementia. “Back then” she felt dementia was something to be hidden.

Learning from the past was an important part of these participants’ journeys to accept their diagnosis and learn strategies to help them cope with changes. Additionally, not all lessons came directly from others with the same condition. Participants were able to learn from both those with and without dementia. Seeing examples of how others were able to overcome challenges were inspirational, but so too were the negative experiences. Stories about people being hidden, isolated and stigmatized taught them how they did not want to live with dementia and how they did not want to be treated. Learning from the past influenced how they thought about the future because they had taken inspiration and motivation from other’s experiences. For these particular participants, these lessons from the past were turned into positives and this, in turn, positively influenced how they thought about the future.

5.1.4 “You Could Play Hide and Seek with Yourself”: Using Humour to Make the Best of It

Humour was a strategy that was regularly used to “make the best” of their diagnosis of dementia. It was used to make light of their situations when they were describing something that was difficult. The following were snapshots of conversations they had amongst themselves in regards to some difficulties they were experiencing. The first conversation below was in response to Joseph talking about noticing his forgetfulness. He talked about leaving things behind at places he had gone in town, and misplacing items around the house.

> Joseph: But I sure notice the — being forgetful, and the big thing is confusion
>
> Joseph: You know, put something down and can't find it, don’t worry about it and spend half the day running around looking for my cap. That’s the way it is

Sophia: You could play hide and seek with yourself [Laughs]

Ben: I'll have to remember that [Laughter]

Joseph: Well, don’t you people forget things? [Laughter]

Ben: I'm not telling you

Thomas: I can't remember [Laughter]

Robert: Are we playing can you top this? [Laughter]

This conversation started a humorous discussion where they were all empathizing with Joseph and letting him know they had experienced the same cognitive challenges. One participant even commented: “Welcome to our world”. Humour about their limitations and decline in condition was a way that these participants made the best of their situation. It was clear to see frustration and sometimes solemnness about these difficulties, but they made light of these challenges and looked for positives. Below was another example where they were making light of the unpredictability of dementia.

Ben: We’re still alive

Sophia: Yeah, you want to believe it.

Ben: That’s right

Joseph: But will we all be here next session? [Laughter]

Ben: I’m not telling [laughs]

Joseph: [Unintelligible 01:25:20] couple dropping off

Thomas: That’s one good thing. You never know.

Ben: You don’t want to.

Thomas: Yeah, that’s right.

Sophia: Every day is a blessing so you may as well use it the best way you can. And stay positive because there’s nothing you can do about it anyways [Laughs] (FG#1 The Past)

This was another example of how they used humour when talking about difficult situations associated with dementia—in this case death and more broadly the uncertainty of their condition. They were joking about possibly not being around for the next focus group. The use of humour as a coping strategy was a way that these participants were able to make the best of their often-difficult situations. In the use of humour, the acknowledgement of a difficult future and the potential for decline or even death was evident, but they chose to stay present and live in the moment. They wanted to live today with enjoyment and not worry about what could come in the future.

5.2 “We Can Do Things”: I'm still capable

The participants in this study described in many different ways their desires to still be seen as competent and capable. Throughout the focus groups, they described their desires to change the dominant tragedy narratives surrounding dementia. While this does not directly speak to people’s perceptions of the future, it demonstrated their desires to create a “today” that challenged dominant discourses of cognitive decline and incapacity. Sophia even spoke to the function of my research as a way to prove to people that they are still capable. She stated: “Where today, you guys – you set up things like this, you know like – that we’re still functionable, we can do things. With a bit of encouragement, you can have strength and whatnot. And that was so missing back then” (FG#3 The Future). She noted the difference between her past and her present. For her, “back then” people living with dementia were seen as incapable of functioning normally or unable to live fulfilling lives. Presently, she believed that this narrative was changing and there were opportunities to show people that those living with dementia were still capable.

Furthermore, Sophia identified that she believed strangers were more likely to have misconceptions about dementia: “It's just when people you meet, some people, not close friends, but they think you can't, they want to do everything for you because they feel you've lost everything. But I straighten them out” (FG#2 The Present). Sophia’s words demonstrate her agency and ability to exert power over others to influence their actions towards her. She expressed her discontent with the way people talked to her with the assumption that she could not understand.

> …oh God, I can’t stand it when people talk to people with Alzheimer’s like they’re not there, you know? Even though they’ve got it and it might take – it just takes us sometimes to go through that little filing cabinet that you have in your head, I have one too, but mine might get a little muddled up once in a while, they must learn to just give us a break for a minute and, you know. (Sophia, FG#3 The Future)

Participants believed that they were still capable and wanted to be treated as such. Sophia made the distinction that although she had Alzheimer’s, her brain was still the same as everyone else’s. She may have required more time or patience from those around her, but she wanted the opportunity to do things for herself.

Furthermore, Sophia took responsibility to show others that their perceptions of dementia were wrong. She stated:

> So, I think, if you treat it positively and upbeat, that’ll show some people maybe that you can still function. You can still laugh at jokes. You can still have a drink. You can still go here, you can go there. Like, it doesn’t end your life. (FG#1 The Past)

More instances of stigma were evident in participant statements where they felt the need to correct the narrative about their condition. Statements such as “I’m not dead” (Thomas, FG#2 The Present) or “Yeah. I can think for myself [laughs]” (Sophia, FG#2 The Present) depicted how influential stigma could be on an individual.

Sophia described how people with dementia can internalize the assumptions that they are no longer capable, and she spoke of the value of one-on-one mentorship for people living with dementia.

> ...somebody walked in here right now and said, ‘My God, I was just diagnosed with Alzheimer's’ I would say, ‘So that's not that bad. Stop and think about it, get to know people in the organization and everything and you'll find out it's not nice but it's not that bad.’ You can still do things. Like people think once you have Alzheimer's your life is over, right, they think you're not capable of doing anything. (FG#2 The Present)

Furthermore, the importance of education was brought up by Sophia as a way to challenge stigma and prove to people they were still capable.

> I'm just saying stigma is a bad thing, it’s usually people got all the wrong impressions. They got the old way, like when I found my mother with it and my, one of my older sisters with it, you know, people hid my mom back in, you know, and that's the wrong, you know, it's nothing to be ashamed of. And it's, you can still live a full life, it just might be a little rough in places but other than that. I mean, we got to rid of that, that is a terrible thing, that stigma. (FG#2 The Present)

Therefore, education was important to correct the narratives surrounding dementia that described it as something to "be ashamed of". Similarly, assumptions about the capabilities of those living with dementia were indicative of misperceptions. Sophia echoed:

> I think a lot of times people figure they have to help you with something. You know, like they just – and I get a little uptight about that at times. But I will say no, no, I'm OK you know, like but it gets on your nerves after a while when they figure you can't do things. You know, but I don't let it bother me, I just go ahead and do it. (FG#4 Member Checking)

Sophia explained that she felt those most likely to underestimate her abilities were people that were not in her immediate social circle. She expressed:

> ... Like my kids and [husband]; they you know, they know what I can do. They wouldn't dare cross me [Laughs]. You know, I'm not that bad. But no, it's – I think it's people outside that don't know enough about Alzheimer's. (FG#4 Member Checking)

Sophia stated: "…and my friends are very good with it, you know. Only sometimes they want to be too helpful. So, then I beat them up" (FG#2 The Present). Experiences of stigma such as these are small instances, but could be impactful. Being "too helpful" could potentially make someone feel less independent.

When asked if other people perceived their abilities differently than they did, two participants said yes, and two participants did not think so. Thomas felt that most people did not even realize he had dementia and as a result he did not experience being underestimated by people that he encountered in his daily life. Similarly, Ben felt that people "don't say too much" but he does not “go around talking about it”. Robert was one of the participants that felt people did underestimate his abilities.

> I’ve been around enough that I can go back and say experience is still there. If I can recall a lot of this, I can repeat it and be helpful that way. I like to help other people who are bothered about things and building and I can offer my advice and offer my two hands to help them. So, there are ways of carrying on like that. (FG#4 Member Checking)

Robert felt that others still needed to recognize his ability to contribute. He knows that he still had a lot to offer people. Lastly, Robert made an analogy that demonstrated the internal dialogue that people living with dementia could have when faced with the public’s perception of them. He described his interpretation of seeing a beaver on a walk:

> He completely ignored us. If a beaver can ignore us, I should be able to do the same with a lot of people and not get excited about what impressions I’m making on them. Just carry on with my own activities and that's my life. (FG#2 The Present)

Robert made this connection when the group was discussing stigma. He used the beaver as an analogy to having ambivalence to other people’s perceptions of him. Robert realized that others might see some of his limitations, but has concluded that their opinions should not get in the way of him living his life.

5.3 “You’re Never Going It Alone”: Finding Solidarity

People with dementia felt a sense of solidarity—that they belonged—when they were able to participate and engage in meaningful activities with others living with dementia. A sense of solidarity emerged among participants, in that they felt that they were not alone in the journey of dementia. Thomas spoke about his experience at a community art program designed for people living with dementia.

> And that’s the one thing that I didn’t mention is the Alzheimer's Society and [home city] Art Gallery, and the artwork there. And we have so much fun doing art and being creative and things, and laughing and having fun, you know. And since it started I haven't missed a session…And it’s well worth it to go there and be amongst people that have the same condition that are —and being creative and having fun. (FG#1 The Past)

Interacting with others who had dementia helped them to make the best of their situations. Ben also talked about the role of interacting with others who had dementia:

> I accept the way I am and I try to do as best as I can and that’s all I think of it in that respect. And doing things with other people that are involved in the same situation has been a good thing, of which I like that. (FG#3 The Future)

Participants also expressed how my research had facilitated another way for them to engage with others who had dementia. Sophia expressed:

> I think that’s the best thing that happened, was this here, where you could talk to people – I’m sorry for interrupting, but that is so important, to be in that group, that you can say anything and you know other people feel the same. (FG#3 The Future)

Ben agreed and stated:

> Yeah, I think you’re absolutely right. I have enjoyed my visits and doing things and understanding that I’m not the only person that has problems and you try to enjoy yourself rather than feel down and out. You know what I mean? (FG#3 The Future)

Robert also expressed that the opportunity to share their experiences as part of this research was beneficial. However, his statement also referenced how interacting with others who have dementia could impact how they think about the future. He stated:

> I think this is a great experience for us to get together this way and just converse with knowing each other briefly. At least this way we can sort of compare notes of what we're doing now and what lies ahead. (FG#3 The Future)

Robert expressed that he wanted to know about other people's experiences so he had an idea of what his future could look like. This further reinforced the idea that finding solidarity with others who had dementia could impact people's perceptions of the future.

Lastly, I asked participants if they believed that being around others diagnosed with dementia was beneficial. All participants agreed that this was important. Ben even admitted that previously he did not engage with others who had dementia, but now realized the benefit. He stated:

> In reality, I haven't done much with other people and talking here tells me that I should be doing it and I haven't in my own mind even thought about it. I don't know why, don't ask but you'll see me from now on. I think I do need more than just the wife to talk with. (FG#4 Member Checking)

I asked if he thought that engaging with others who have dementia would be positive, to which he replied:

> I think it will, yes. I was staying, staying out of that because I thought I was making mistakes and stuff, so. And by staying away from it I think I put – I made it worse for

> myself, so. This was a good thing to talk and see what other people are doing. I thank everyone, thanks. (Ben, FG#4 Member Checking)

Sophia further echoed that being around others with dementia meant “You’re never going it alone” (FG#4 Member Checking). Participants believed that being around others was positive because there was solidarity in being around those with the same condition.

Furthermore, finding solidarity with others who have dementia also had the potential to positively influence how they thought about the future. Robert talked about a program designed for those living with dementia and stated it has changed how he thought about the future.

> Yes, it has. [organization 1] has been a real Godsend to me and to both of us. We go, we meet with people we’ve never met before but we also come in contact with friends that we haven’t seen very much of it and this is a chance to get together again. It’s a very positive approach that we’re using here with you people. All of you because we’re all in this together. We’re only passing this way once. (FG#4 Member Checking)

Robert felt being around others who had dementia positively changed his thinking. He further echoed:

> It gives me a chance to be positive, to ignore any little problems that I have. I want to get out there and I want to talk to people; what are you interested in doing? Have you done any trips? Have you travelled? Have you done puzzles? What are you interested in doing? And the answer is well, not much. (FG#4 Member Checking)

Taking interest in the lives of those living with dementia showed that Robert had found solidarity with these individuals. He wanted to “talk to people” which demonstrated the importance of engagement. The types of things he wanted to talk about were also important. He was not necessarily asking them about their condition, but was asking them more broadly about their lives (hobbies, likes/dislikes) which showed that he had a positive outlook on the futures of those living with dementia. He did not assume that people's lives were over, he knew they were not.

5.4 "A lot of our life right now is planning ahead": Life is Ahead of Me

This section captures how participants talked about their lives and their futures through a number of subthemes, including "carrying on", "staying socially engaged", and "charting a new path". Participants viewed their lives as still ahead of them, with much more life to live, things to do, and relationships to nurture. While their lives may have changed as a result of dementia, their lives did not end. No matter how many times participants demonstrated their awareness of the progressive nature of their condition, they also expressed sentiments about continuation. Although *the future* seemed like an abstract concept, continuation meant that these individuals had an expectation for the life that lay ahead of them.

This continuation was sometimes explicitly discussed as future plans, and others would simply talk about what they intended on doing but had yet to do. One example of this was Robert, who expressed that he did actively make plans for the future:

> So, we do make plans ahead and I think that's true of a lot of our life right now is planning ahead. Not just for the day, look what's going to happen in a week from now or further down the road. (FG#2 The Present)

For Robert, making plans was something he looked forward to. Plans ahead included distant plans for activities and travel, but also shorter-term plans for the day or week. Robert expressed:

> I look forward to getting the paper from under the door every morning. It sounds silly but that means the day has started. And we bring that in and we share the sections, we discuss things. So, if we start the day off on a positive note, thinking what is lying ahead, what is in here that we might be interested in doing or experimenting with. So, we've always come up with something that's positive for the day. (FG#2 The Present)

Robert made the distinction between making sure he started his day on a positive note (FG#2 The Present) and thinking about what could possibly be "lying ahead" (FG#3 The Future). He both lived in the present and enjoyed moments such as getting his paper every morning, and used the paper to find inspiration for what he could do moving forward.

5.4.1 Carrying on

Carrying on described how participants continued their daily lives, while recognizing their limitations and adapting to them. Sentiments such as Ben's depicted this recognition: "Well, yeah, I certainly realize you can't do the things that you used to do" (FG#3 The Future). Ben recognized that there are some things that he could not do anymore. Even though all participants shared the same recognition of their limitations, they still wanted to remain engaged in things that they enjoyed.

Robert and his wife still continued to find ways to travel. Robert stated: "I think a problem is that there are a lot of countries that we are on a list that we have to go to sometime, but we have to be practical too" (FG#3 The Future). Robert had travelled a lot in his lifetime and still looked forward to doing more. However, he knew that his potential decline could impede his ability to do things the way he used to. This made Robert want to take every opportunity he could while he was still able. Not only did this include travel, but also spending time with his son that lived in another city. He expressed: “We want to spend some more time with him while we’re still able to” (FG#3 The Future). Recognizing limitations demonstrated that these individuals have thought ahead to what dementia could mean for them in the future. They were aware that further decline could result in a change in their abilities but they were still carrying on with life.

Carrying on with one’s life meant taking control and finding ways to do what you desired to do. When trying to manage a condition with an unpredictable trajectory, feeling accomplished was a way these individuals gained a sense of control. Robert talked about activities in the city that enabled him to do this: “But there are activities like that in the city that we can just go out and come back and say we've accomplished something today and that's a big factor” (FG#2 The Present). Moreover, Robert considered specific activities that he would like to carry on doing.

> I guess it’s planning ahead of things we like to do. Travel is one of them definitely. I still enjoy going for walks and if I do I say I’m taking my camera with me because I like to photograph as we go. Like you come back with something that says this is what I accomplished today. And I think that’s important for all of us so, that we can say – even little things are accomplishments. (FG#4 Member Checking)

This further reinforced the idea that the activities they engaged in were not random. They were things they enjoyed doing, and had a purpose. In this way, carrying on was tied to their abilities.

Carrying on was finding a way around their challenges. Robert felt that his past experiences had given him a great deal of knowledge and he could help people by sharing that. For him, this was a way he could carry on engaging with others.

5.4.2 Staying socially engaged

The importance of remaining both socially and physically active was another way participants demonstrated that their lives were ahead of them. This was very apparent during all focus groups and among all participants, but it was also evident that they valued both interactions with those who have, and do not have dementia. To begin, Sophia expressed the value of remaining social in broad terms. She expressed: “Being social is the best thing in the world for people like us” (FG#1 The Past). Being social was tied to inclusion, tied to functioning, and was crucial to how these individuals were able to cope with their diagnosis. Overall, continuous engagement in activities that were enjoyable was a part of re-storying their future. Their lives did not end with a diagnosis, and they continued to participate in things they enjoyed.

Being engaged, not just for the sake of participation, but in activities that they enjoyed demonstrated their ongoing engagement with life and that they viewed their lives as being ahead of them. Participants enjoyed being outdoors, continuing hobbies, and being social with friends and family. I also asked about specific plans, if any, that they had made for the future. It was apparent that most individuals only took their life day by day; future plans tended to be related to activities to stay socially engaged rather than major life changes. However, one plan that stuck out was the following. Sophia stated:

> …I’d like to help somebody who’s been diagnosed with Alzheimer’s and is in a panic. Because to me I had the right people and that was your group and it’s helped me 100 and I can’t even say it percent. (FG#4 Member Checking)

She spoke about the profound effect that being socially engaged and developing a support network had on developing a positive outlook about her condition. She talked about organizations that she was involved in as well as the opportunity to interact with an individual who also had dementia after she was diagnosed. She too would like to be that support and advocate for someone who had been recently diagnosed or was struggling with their diagnosis.

5.4.3 Charting a new path

Charting a new path meant that participants had found a new path after their diagnosis of dementia. While not all participants described this, Sophia in particular described how her diagnosis of dementia led her to become a different person and chart a new path. These individuals openly talked about some of the decline that they had noticed in themselves. The important part was that they acknowledged it, and had found ways to keep moving forward, be engaged, and live fulfilled lives. The following quote showed how Ben described his decline: “You know, you have mental problems and you don’t … But, it really caught me. And that’s when I realized that I had problems” (FG#1 The Past).

Ben noticed changes in himself. He still notices them, but he has chosen to keep moving forward. Furthermore, quotes such as: “sooner or later all these things are going to come” (Robert, FG#1 The Past) is another example that shows these individuals are aware of potential decline in the future. Robert was referencing the potential of not being able to participate in a hobby that he loved doing. Sophia spoke up in agreeance and said: “They’re going to change again, yeah” (FG#1 The Past) to which Robert responded: “So, do it now. Enjoy it now” (FG#1 The Past). None of the participants have let their fears of losing something stop them from living a fulfilling life. Robert also demonstrated his ability to find a new path when he said: “Maybe I'm missing out on a lot of other things, but I can still” (FG#1 The Past). They have all expressed they are happy, and have accepted their condition. However, just because someone has expressed they are at peace with what might happen does not mean that it is no longer difficult. Rather, they have demonstrated that they have been able to incorporate dementia into their lives, and find a new path living with this diagnosis.

Sophia talked about her ability to find new paths around her changing abilities. She expressed: “There’s things I've always done; I've cross-country skied, I've downhill skied, everything. Those things are gone for me. But that’s OK, I'm going to find another path, you know, but I'm not going to let it get me, you know, no matter what” (FG#1 The Past).

Dementia was not going to get the best of her. If she was unable to do something as a result of her condition, then she was going to find something else to do. In addition to finding new paths that related to their abilities, Sophia also talked about the “new person” that dementia created.

> And [Husband] is so amazing with it, I mean, he lets me do my own thing and doesn’t talk for me, like some people want to speak for me all the time. Like if I pause too long they want to talk for you. [Husband] doesn’t do that. Thank goodness because I told him I’d cuff him one if he did. Because there’s a new person out here now, he’s got to learn to live with her [laughs]. (FG#3 The Future)

Sophia had not only noticed a change in her abilities, but she thought of herself as a new person. Previously, Sophia had stated that she “never had that much confidence” before being diagnosed with dementia. She expressed how she now felt like an expert about her condition and she continually demonstrated her willingness to speak out on behalf of others living with dementia; this was a new path that she was on. For example, Sophia stated: “I would never, ever, ever have done anything like this in my life. I would never speak about anything because I've never had that much confidence, eh. But now I figure I know it [laughs]” (FG#2 The Present).

Sophia was more shy before she was diagnosed and has found a new confidence in herself. She believed there was no better person to educate others on dementia than someone who was living with it and that gave her power over others. Not only did she desire to educate those who do not have dementia about her condition, she wanted to support others who have been diagnosed as well.

> I would work until the day I die…with Alzheimer's or people with dementia, whatever, just to show them there is – you can have a good life, but you have to – it's like anything else, you have to work to get it, right? So, if we can just stay positive, think of the right things, have good people around you, it's amazing, really. (FG#3 The Future)

This quote demonstrated that Sophia had a positive outlook on the life that was ahead of her—her future. So much so that she wanted to share that with other people who were diagnosed with dementia. Her sentiment about "you have to work to get it" showed that she feels capable of achieving that good life. Robert also pointed out a positive change since he was diagnosed. He stated: "I developed more patience, I had to" (FG#2 The Present). He now finds that he does more physical activity, and spends more time reading than he used to. A diagnosis of dementia could be associated with negative changes. However, these participants had also found positive changes as a result of their diagnosis. Acknowledging both the positives and negatives aided in their ability to cope and focus on the life that was ahead of them—their future.

5.5 The Future is measured by pivotal moments

The future was measured by pivotal moments. These were moments when individuals were no longer able to participate in things that were important to them because of their cognitive decline. Each individual had a different measuring stick or benchmark that they utilized to assess their rate of decline, typically in relation to something they could no longer participate in.

Driving was a significant pivotal moment. Sophia was no longer able to drive, and she stated, "I never realized how much I used my car until it was gone, or how independent I was" (FG#1 The Past). For Joseph, this was his biggest fear: "But that's my biggest fear is losing my license. I've driven since I was a kid" (FG#1 The Past). No longer being able to drive was a pivotal moment when they recognized their cognitive changes. Losing one's license or ability to drive was one example of something that was tied to independence. Three of five participants no longer drove, and only one of them was happy about that decision. For example, Joseph still drives, but his above quote showed that losing that was his biggest fear. For him, not only is it independence but it is part of his identity.

Robert particularly, named a beloved hobby as the way he would know that he had experienced significant decline.

> Well I've been interested in photography all my life, and when I can no longer pick up a camera and figure out how to use it, that'll be the saddest day for me, because there's so much pleasure in doing that. Don't put me behind the wheel. You drive the car and I'll use my camera. But we know that sooner or later all these things are going to come. (Robert, FG#1 The Past)

Robert also stated: “That tells me I am still there” (FG#1 The Past). He is referencing his ability to continue to partake in making albums about his travels, which is something he finds great joy in. The day when he could no longer use a camera represents a pivotal moment in the future for him, one that he is not looking forward to and one that marks significant cognitive decline.

Another significant pivotal moment that was brought up by participants was the potential placement in a long term care home. Robert stated: “I don't know about you gentlemen but I asked my wife, I said ‘No matter what happens to me please don’t put me in a home’” (Robert, FG#1 The Past). Robert did not want to go into long term care and this is a sign of decline that he had no control over. He expressed that his wife said as long as he maintained the way he was, she would not need him to be placed in long term care. This alluded to not only what decline meant to someone living with dementia, but what it meant for others in their life. Robert would be put into long term care when his *wife decided* that she was unable to manage his condition at home; therefore, she would decide when this pivotal moment would take place.

It was also interesting to note that Ben stated he had a “good wife” for agreeing that she would keep him home for as long as possible. This demonstrated that long term care was something other participants had considered for their future as well. However, Robert responded: “Now she doesn’t have to hold that promise. At this stage, I've done so well” (FG#1 The Past), and “I couldn’t ask for any better life or a better wife” (FG#1 The Past). Although long term care is not something that he would necessarily choose or want for himself, he did not want to be a burden to his spouse and seems to have accepted that this could be a part of his future.

Similarly, Thomas talked about his experience with his mother who was diagnosed with Alzheimer’s and placed in long term care. He stated: “…the last time I saw her she was in an institution behind a cage with others. And, yeah, it wasn't good” (FG#2 The Present). He further said: “It made me cry” (FG#2 The Present). Thomas brought up this conversation during our discussion on stigma. He believed that his situation was “completely opposite to what she went through”. He believed that long term care was a negative experience for his mother and referenced that she had previously lived alone, and Thomas did not. This was a pivotal moment for Thomas and shaped how he thought about his future. He weighed his mother’s experience going into long term care against his own.

Sophia had a more positive experience with long term care than Robert or Thomas did. She talked about her sister who also had dementia and was currently living in long term care.

> I have a sister in [different province] who's about 10 years older than I am and she has it. But when I talk to my nieces down there they say she is so happy there and of course they showed me a video of her dancing and carrying on like she would normally would be. So, things are getting better, it's just slower, you know. I mean, it's, it's not a thing that's going to happen overnight or whatever. But, and I was talking to her husband and everything and he said, "She's so happy there, [nickname]" – they call me [nickname] – "she's just so happy there, [nickname]." It's just, like it's nice to see her, so. (FG#2 The Present)

Participants’ perceptions of the future were measured by pivotal moments such as losing the ability to drive or participate in hobbies, or the prospect of transitioning into long term care.

5.6 The future depends on relationships and family

Participants described their future, particularly related to care needs, as being dependent on relationships and support. Family played a critical role and provided support in different ways. Having family to “brighten my life up” (Sophia), or facilitate engagement in activities was a lot different than relying on them for basic personal needs. In this way dependence and support were different, and dependence was not accepted readily by participants. Sophia specifically addressed her concern in regards to becoming dependent on her family for basic personal needs.

> If I got to the point where I needed nursing care all the time or whatever, or I didn’t know where the bathroom was or whatever, all that, put me in a home, because I don’t think it’s fair to leave me … I don’t think it’s fair to [Husband] or my one daughter that lives here to have to look after me like that. (FG#1 The Past)

Sophia did not want to depend on family, or have her decline be at their expense. One participant chimed in and told her that it would be ok to stay home because her family would want to take care of her, and she should not feel guilty. However, she referenced her past experiences watching other family members going through dementia and how difficult it was for their family to take care of them; something she did not want for her husband or children. Even though she has recognized that this could be in her future, she did talk about long term care as being a last resort option, and thought she would have to be “really bad” before she would “give in”. Her perceptions of the future had been shaped by her relationships both in the past and the present and it had influenced how she thought about her future.

In contrast to not wanting to be dependent on family, their support and encouragement to remain socially and physically active was crucial as it related to independence. Sophia stated: "…it has changed me in a way that I can't, I'm not as independent as I was, that's the killer, not being, you know, so. I hate having to depend on other people, you know" (FG#2 The Present). She recognized that there were situations where she would need support from her family. One example of support that she has received from her husband was a GPS app on her phone. Sophia enjoys going for walks but fears getting lost. Her husband installed the app on her phone so someone could always find her if she went for a walk and got lost.

Furthermore, family members helped facilitate engagement, and aided in developing strategies to cope with their diagnosis. Robert expressed:

> Well, I find that [wife]'s encouraged me to write things down rather than trying to just remember them and that's been a big help. So, there's a daily plan of activities that we're planning to do and we plan this out and talk about it. (FG#2 The Present)

Support from family facilitated some of their independence. Remaining engaged in activities they enjoyed doing, or finding ways to cope with changes they were experiencing allowed them to remain independent. Support of family was important to remain independent into the future.

Spousal support was most often cited in instances of encouraging engagement and aiding in coping strategies. Even though it was important for participants that their family was supportive of their continued involvement, their companionship was just as beneficial. Statements such as: "I don't think I'd have a future if I didn't have them" (Thomas, FG#3 The Future), "My wife is my best companion (Thomas, FG#2 The Present), and "We work as a team (Robert, FG#3 The Future) demonstrated that family was an integral part of their future. Not just to support their engagement but for companionship. Sophia also expressed the importance of her family beyond helping her with changes as a result of her condition.

> Because I'm going to need them now [laughs]. I won't be able to look after myself. No, because they brighten my life up. Everybody has something to offer. They make you feel better about yourself or where you can go or whatever. They're just very important. I don't know what I'd do without my daughters and … well my family, my immediate family, who's living still? (Sophia, FG#3 The Future)

These individual's family provided them with support. Participants found joy, and their relationships undoubtedly aided in not only their coping abilities but the positive mindset required to reach acceptance of their diagnosis. Thomas also talked about the importance of his friends and family, especially since COVID-19 had kept them away.

> I think my future looks good. You know, it looks good because we have a number of friends here that we haven't seen in a number of weeks and then our family, we totally enjoy our family who generally come here almost every other day or every day. Those kinds of things, it's important for [Wife] and I. (Thomas, FG#3 The Future)

Thomas talked a lot about his family and friends. It was apparent that the social connectedness and support system he had was crucial. This was a major asset in his ability to cope with a diagnosis of dementia. In one of the previous quotes about him seeking counselling, his wife was with him, and when he talked about the future he talked about his family. Thomas looks forward to spending time with them. His support system positively influenced his perceptions about the future.

Furthermore, I asked participants if they felt that those with dementia thought about their future differently than those not diagnosed. When I asked Robert if he felt that he thought about his future differently than those not diagnosed with dementia he believed people could approach the relationship differently.

> I think they deserve a different kind of approach. I think you have to be very close to them and you have to take time to introduce yourself and to come up with something in common. Information that you would want them to converse with. So, it's not just the case of asking questions; it's a case of building a little bit of a bridge first of all. Does that make sense? (Robert, FG#4 Member Checking)

This demonstrated that he did not believe people with dementia thought differently about their futures, but their futures could be different. Robert stated that he liked to build those bridges with people. *Building bridges* to me, represented connectedness. In that respect, relationships can be very important for those diagnosed.

For most participants, future plans most often included spending time with family and continuing to do what they had been doing all along; which I believed further reinforced that they do not think differently than those without a diagnosis. Quotes such as: "I just want to have a good time and enjoy my life with my family" and "You know that you've got a problem, live with it and enjoy the rest of your life. That's what I want to do" demonstrated that they were living in the moment and continuation of that was the future for them.

In summary, the themes within the findings could be divided into two broad categories. "Making the best of it" (and its subthemes), "I'm still capable", "finding solidarity", and "life is ahead of me" (and its subthemes) were about the present future. That meant participants' focus was on incorporating dementia into their lives and thinking ahead about what they would experience in their day to day such as things they wanted to carry on doing. The themes “the future is measured by pivotal moments” and “the future depends on relationships and family” related to the distant future. In this section participants identified loss of cognitive ability and capacity in the distant future. All of these themes helped to determine how participants’ perceptions of the future had been influenced.

Chapter 6: Discussion

The purpose of this research was to explore people with dementia's perceptions of the future since being diagnosed. The future to those with dementia was complex. It was not solely the distant future—thoughts about decline or death—that characterized their thoughts of the future. There were two main ways of thinking about the future—the present future and the distant future. It was the present future—their ways of making the best of things, showing they were capable, and finding solidarity with others living with dementia—that they described significantly. While the distant future was also described through pivotal moments and the support of family, it was not their sole focus. These individuals' perceptions of the future had changed since diagnosis, and may still continue to change. Their relationships with others and their ability to learn from the past all impacted their perceptions of the future since being diagnosed with dementia.

6.1 Coping with Dementia

6.1.1 Making the Best of It

Participants' ability to make the best of their diagnosis was an important part to re-storying their lives. It meant that they were able to incorporate dementia into their lives, and when it impeded their ability to do something they found ways around it. This combination of incorporation and adaptation linked back to the development of a person's identity. Harman and Clare (2006) described a cyclical process that consisted of maintaining who they were before and combining new aspects of themselves since being diagnosed. This cyclical process also linked to the idea that participants pasts, presents and futures were being drawn upon in the same fashion to make the best of their diagnosis.

6.1.2 Finding Solidarity

Finding solidarity was something that emerged out of this research and had not previously been considered in the literature review. The importance of relationships had been explored, such as how families had the ability to empower or disempower those living with dementia (Wiersma et al., 2016) but not specifically the relationships they had with others living with dementia. Relationships with others who have dementia has been emphasized because it allows for meaning making (Ward, Howorth, Wilkinson, Campbell, & Keady., 2012). Furthermore, such interactions did not have to require discussion of their condition, just their engagement amongst each other was important (Mason, Clare, & Pistrang., 2016) and these positive relationships aided in dealing with the potentially negative aspects of dementia (MacRae, 2011).

6.1.3 Life is Ahead of Me

Participants' belief that their life was not over was an important finding of this research. Upon diagnosis, people have to come to terms with their diagnosis (Robinson et al., 2005) and this was important for these participants. They all expressed they had accepted that they were going to live with dementia, and that allowed them to move forward. Harman and Clare (2006) discussed the balance between dealing with changes and still living a fulfilling life and this was evident in these participants. They had incorporated dementia into their lives and expressed that they still had a good outlook on their future. What my study added to the literature was how people incorporated dementia into their lives and how they perceived their future moving forward. Participants' pasts, present and future were all important in shaping how they perceived their lives moving forward. This study focused on those perceptions rather than what they had done or were doing to achieve that balance between incorporating dementia and continuing to live a fulfilled life.

All of the above themes address people with dementia’s ability to cope with their diagnosis. To cope is: “to deal with and attempt to overcome problems and difficulties” (“Definition of cope”, 2020). The participants of this study showed that they were able to overcome difficulties as a result of their condition. They made the best of their diagnosis by incorporating dementia into their lives, found solidarity in being around others with the same challenges, and ultimately believed that life was ahead of them. They took action to deal with their challenges and as a result they had a positive outlook on the future.

6.2 Stigma and Dementia

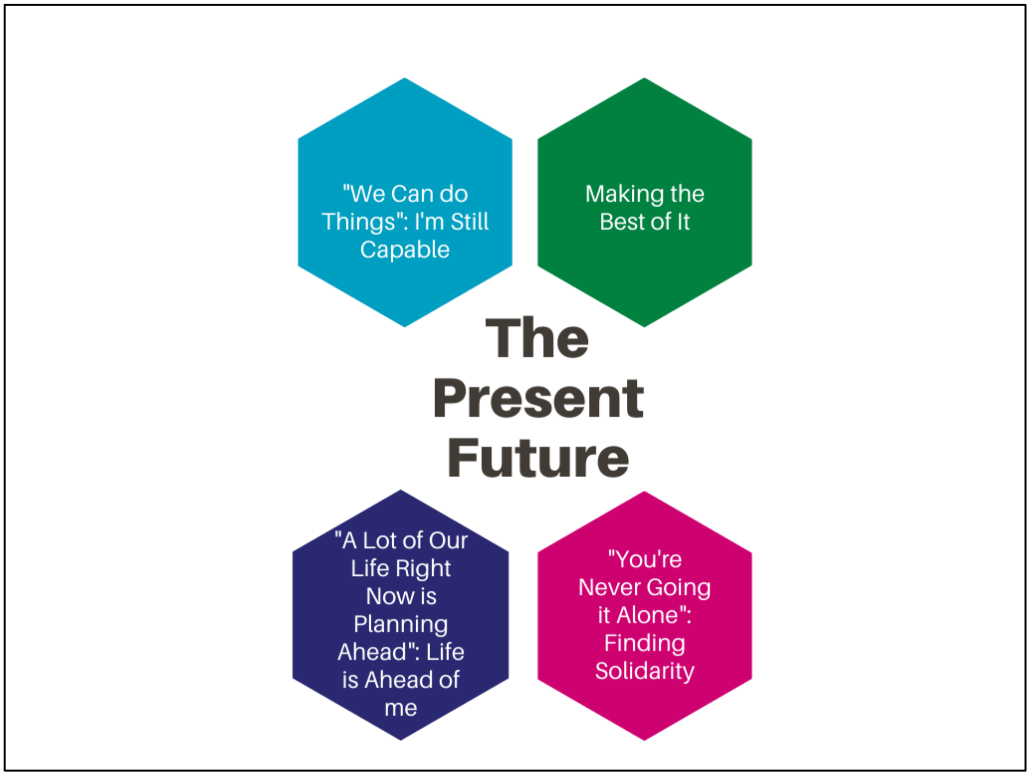
6.2.1 I’m Still Capable

Furthermore, participants wanted to show others they were still capable. Stigma played a role in their desire to change the narrative surrounding dementia, and they explained how misconceptions about dementia could cause others to underestimate their abilities. Stigma is experienced by people living with dementia (Alzheimer Society of Canada, 2019a; Burgener et al., 2015) and it is important to challenge these assumptions (Johannessen & Möller, 2013). Stigma had influenced how these participants thought about their futures and this was something that had not been identified in literature. Previous research speaks to the impact it has on the individual, but not on their perceptions of the future more specifically. The participants of this study sought to be seen as capable, and change the narrative surrounding their condition that emphasizes cognitive decline and incapacity. These individuals were able to overcome these views of dementia and it did not negatively impact their overall outlook on the future. However, they were aware of the impact stigma could have on an individual.

Stigma to these participants was always negative. For them, misconceptions about what it meant to have a diagnosis of dementia was the cause of the stigma they experienced. This related to people's assumptions about their cognitive ability and what they were still capable of doing. An important point that came out of the findings was that education was a way to combat this stigma. If people were educated about dementia, then they would not assume that those living with dementia were no longer cognitively capable. People living with dementia are the best people to educate others about what living with this condition means. The themes discussed in this section represent the *present future* of those living with dementia. (See figure 2 *The Present Future*)

Figure 2

The Present Future



6.2.3 The Future is Measured by Pivotal Moments

Pivotal moments were undoubtedly a measure of participants' futures. As discussed in the literature, a diagnosis of dementia was the initial biographical disruption. Receiving that diagnosis included various experiences and responses (Pratt & Wilkinson, 2003; Robinson et al., 2005; Vernooij-Dassen et al., 2006) but how it impacted their perceptions of the future were not identified. Moreover, past experiences of others impacted how they perceived other pivotal moments that may be a part of their future. These moments included loss of the ability to drive, inability to participate in important creative pursuits, and transition into long term care. Participants' perceptions were shaped by these moments in time and it impacted how they perceived their own future living with dementia.

People with dementia's perceptions of the future is an important addition to dementia literature. By delving deeper into what could influence their perceptions we can determine what has the potential to positively or negatively impact their thoughts about the future. In this study, the future was divided into two parts, the present future and the distant future. It exemplified that continuation of their day to day (present future) was just as important as pivotal moments in the distant future. Conceptualizing cognitive decline and loss in the distant future aligns with the nature of progressive illness; their condition will most likely worsen. It is important to have those conversations and be prepared and educated about these potentials, but so too are the conversations about the present future. Talking about the present future means that we encourage those living with dementia to continue doing what they love, adjust when needed and make the best of their condition.

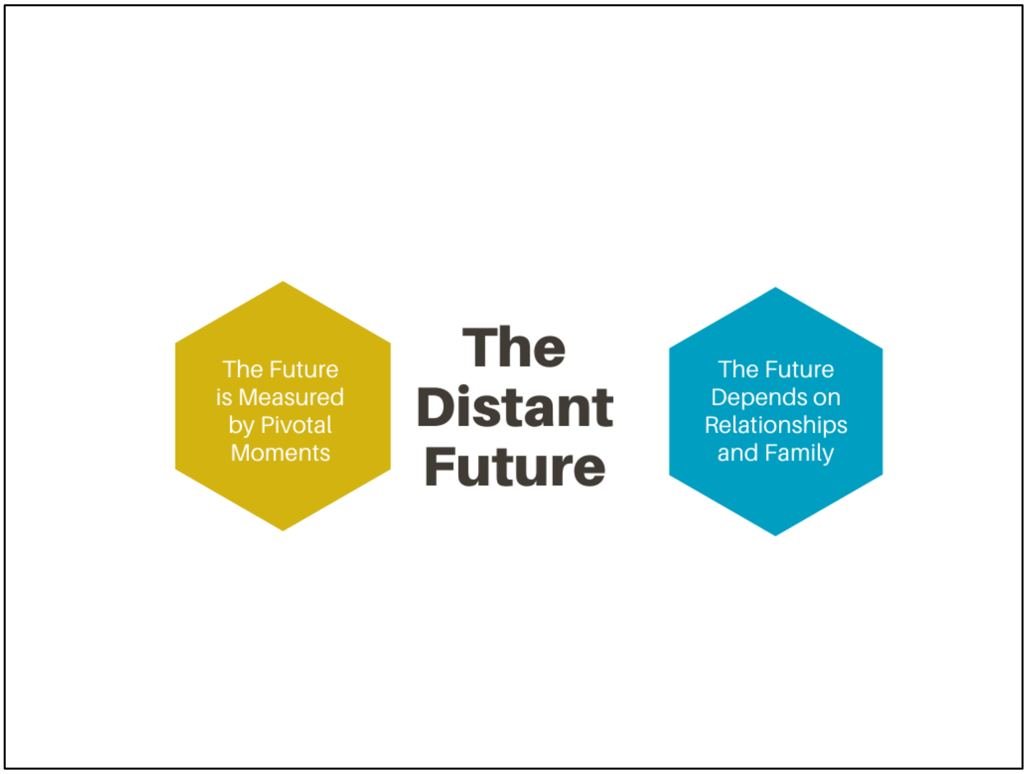
6.2.4 The Future Depends on Relationships and Family

The future of these participants also depended on their relationships and family. Kitwood (1997b) reported various ways that an individual could cope with their diagnosis that included relationships, personal experiences, internal resources, interpersonal relationships, and their environment. This was certainly the case with the participants of this research who learned lessons from their past about internal resources (determination, perseverance), and the benefit of remaining socially engaged. Specifically, in regards to relationships Kitwood (1997b) spoke about psychosocial needs that related to being loved. The importance of examining the relationships and the impact they have on people's perceptions of the future was a key component of this study. People do not experience their future in isolation. Furthermore, studies about people living with dementia who fear being a burden (Alzheimer Society of Canada, 2019a; Clarke et al., 2012; Johannessen & Möller, 2013) were also reflected in this study's findings. Participants wanted support from their relationships, but did not want to be dependent on them.

Relationships are crucial to how people with dementia think about their future. Support of family and friends aided in maintaining independence and an overall positive outlook on the life that lie ahead. It was important to examine how impactful these relationships were on their perceptions of the future. If the participants of this study described how influential the people in their life were in maintaining a positive future perception, then relationships could have the potential to negatively impact future perceptions as well. It is not just about examining how best to support someone living with dementia, it is examining how impactful support could be on that individuals' perceptions of their future. The following figure is a depiction of the themes within this section that make up the distant future for those living with dementia. (See Figure 3 *The Distant Future*).

Figure 3

The Distant Future



6.3 Biographical Disruption

Biographical disruption was the framework I used to shape my study. Biographical disruption described an internalized experience of finding out that one was diagnosed with a chronic condition and how individuals utilized their biographies to re-story their lives post diagnosis (Bury, 1982). In this theory, receiving the diagnosis was conceptualized as the disruption—a pivotal moment in time where people realized that the trajectory they believed their life was going to take had changed. After doing this research and analyzing the data I realized the diagnosis of dementia was not the sole disruption. Chronic progressive conditions were inherently disrupting people's lives. The diagnosis was arguably what set this re-storying process into motion, but especially with a diagnosis of dementia, not only was there progressive decline, but the rate and instances of decline were different for everyone.

I first noticed this when I asked about coping. Participants were continually being challenged to find new ways to continue to do things, or find new ways of maintaining both social engagement and engagement in physical activity. In this way, instances of decline or loss of ability were also disrupting to these individuals lives. It is also important to note that although words such as *decline* and *loss* are being utilized when describing disruptions, this should not always be interpreted as a negative experience. It was clear that these participants were happy with life, and although they faced challenges, they were able to keep a positive attitude and make the best of their diagnosis. In sum, disruption did not just occur at diagnosis and did not have to be interpreted as negative. Rather, disruptions were cause for a continual ability to adjust.

In addition, because the purpose was to uncover the biographies of my participants and the ways in which they could have influenced their perceptions of the future, the importance of time became all the more apparent. Focus groups about the past, the present and the future elicited stories from growing up until present. They talked about family, jobs, and prior experiences of dementia. This not only gave context, but it illuminated how their ability to accept their diagnosis and re-story their lives had influenced and continued to influence their journey living with dementia. Participants continued to draw on their past, which demonstrated the influence it had on their current mindset. Furthermore, their stories foreshadowed how those lessons were going to be brought into the future. Biographical disruption was successful in providing a framework to conceptualize the experiences of these individuals and delve into how their biographies over time helped form their strategies to live fulfilled lives with dementia.

However, in adopting a biographical disruption framework to conceptualize the experience of individuals living with dementia I learned that it was not linear. Their biographies had developed in a linear fashion over their lives, but how they drew upon or utilized those times to aid in living with their diagnosis was cyclical. Their past, present and future were intertwined and participants were unable to talk about them in isolation. Re-storying their lives also included their ability to maintain what they were doing in the present in the face of decline. Although participants experienced changes in ability, they still found ways to engage in activities that brought them joy. Participants looked to maintain what they had always done, while being prepared to find a new path if needed. Paying attention to their past, present and future was acknowledging what had made them who they were, and could help others determine how to best support them in living with dementia. Ultimately, people's biographies had influenced how they thought about the future.

6.3.1 Biographical Disruption: Current literature

Biographical disruption was a theory developed by Michael Bury in 1982. It was developed for use in chronic illness literature more generally, but was used in this research as a conceptual framework to examine the data. This theory has been adapted, utilized and criticized quite extensively in chronic illness literature, but not so for dementia specifically. This could be because there were tensions identified in regards to how dementia was categorized. Kydd and Sharp (2016) suggested that dementia could actually benefit from being categorized as a chronic condition, disability and terminal illness. This ambiguity surrounding how to categorize dementia could have been one of the reasons why dementia rarely showed up in chronic illness literature pertaining to biographical disruption. The studies that did mention biographical disruption and dementia did not utilize it as a conceptual framework that sought to determine the perceptions of the future for people living with dementia. Studies such as (Karner & Bobbitt-Zeher, 2005; Tolhurst, & Kingston, 2012) used theories that built upon or were similar to biographical disruption. However, these studies were not about the perceptions of the future for those living with dementia.

6.3.2 Time

This study was designed with the conceptual frameworks of biographical disruption and social citizenship. To begin, biographical disruption informed the methodology of this study. This framework was chosen because I wanted to uncover not just the perceptions of the future for people with dementia, but what had influenced those perceptions. Examining their biographies was a way to do this, as people's experiences happen over time. That led me to design my focus groups as the past, the present, and the future. Even with this rationale, I did not label my study as one about time. However, it was evident that time was a factor that played a role in forming people's perceptions of the future since being diagnosed with dementia. This required a search for how time had been represented in chronic illness literature.

In a narrative review, Jowsey (2016) explored how time and chronic illness had been studied. This review did not specify what type of chronic illness research had focused on, and only excluded articles if time had not been analytically or theoretically applied to the study (Jowsey, 2016). In total only 40 studies were included which represented the body of literature from 1970-2013 (Jowsey, 2016). Jowsey (2016) identified four main temporal structures: calendar and clocked time, biographical time, past-present-future time, and inner time and rhythms. The article found that calendar and clocked time was the most dominant temporal structure used by western societies, and most studies reported on people who were experiencing severe illness or had little life left to live (Jowsey, 2016). The author found that the meaning of chronic illness was created “over and in relation to time” and was important to their overall biographies (Jowsey, 2016, p. 1099). Jowsey (2016) noted that understanding the meaning of time in relation to one’s chronic illness was an important understanding, but adding “the implications that the illness holds for their previous, present, and future actions” created a more complex understanding of the experience of chronic illness (p. 1099). Jowsey (2016) concluded that research that aimed at understanding the experience of time—especially those that recognize the ability of people to use more than one—could be of more benefit than those that do not consider how time impacted the experience of chronic illness.

In relation to my study, time was another layer to understand how the participants perceived their future. Their biographies represented the concept of biographical time, as well as the use of past-present-future time which illuminated the cyclical nature of drawing on experiences— throughout their biographies—that had influenced those perceptions. There was also an important way that participants spoke about their future, which related to a unique perception of time. They perceived two types of futures—a present future and a distant future. It was clear that time meant more than one of the four temporal structures that Jowsey (2016) had described in the narrative review. Further research could explore deeper meanings behind how time plays a role in people’s perceptions of the future related to dementia.

6.4 Social Citizenship

It was both difficult to know that these individuals felt they had to correct the narrative surrounding dementia, and encouraging to know they recognized the power they had to do so. Stigma played an important role in these individuals’ lives. Arguably these participants were in a position of power because of their involvement in organizations that facilitated their ability to remain engaged and advocate for others with the same condition. However, it was also apparent that accepting their diagnosis required the support of family and friends. Wiersma et al. (2016) noted that it was crucial to understand the role that families play in empowering and disempowering those diagnosed with dementia. It can be argued that the close relationships that these individuals described, and the agency they expressed could, in part, be attributed to their empowerment.

Furthermore, when discussing what the future was for someone with dementia they often described continuation of activities and spending time with their loved ones. All participants in this study were able to make choices for themselves and demonstrated their agency not only by taking physical action but by making interpersonal decisions as well. Such decisions included choosing to accept their condition and the difficulties that it may bring.

This linked back to the social death (Sweeting & Gilhooly, 1997) experienced after receiving a diagnosis of dementia and the perception that these individuals have lost what defines them as human. This narrative is evident in literature that debates capacity, and emphasized by biomedicine where individuals are to be cured of ailments. The reality is dementia cannot be cured. Being diagnosed with dementia places a label on them that is like no other condition.

To further emphasize the impact of social citizenship it is important to examine Bartlett and O’Connor’s “principles of social citizenship”: growth, social position, purpose, participation, community, and freedom from discrimination (2010) and how they related to my study. To begin, growth meant movement or change (Bartlett & O’Connor, 2010) and this directly related to the theme “making the best of it” where participants were focused on acceptance and living with their diagnosis the best way they could. This required change, and forced them to incorporate those changes in order to enable their continued engagement in what they enjoyed doing. The theme “I’m still capable” related to freedom from discrimination (Bartlett & O’Connor, 2010) where the authors described how fear and safety could impact an individual’s engagement. For the participants of my study this related back to stigma, and how misperceptions of what it meant to live with dementia—such as underestimating their abilities—had the potential to hinder their independence, and ultimately affect their perceptions of the future. “Finding solidarity” related to community. Community referred to being the expert on living with their condition (Bartlett & O’Connor, 2010). Being around others with dementia reinforced that they were not alone in what they were going through. Furthermore, the theme “life is ahead of me” was tied to purpose (Bartlett & O’Connor, 2010). Participants believed that the life ahead of them was going to be fulfilling and they still had reasons to look forward to their future. Similarly, “the future is measured by pivotal moments” was related to community (Bartlett & O’Connor, 2010). Participants believed they were experts in their condition and had found courage (Bartlett & O’Connor, 2010) when challenged with adversity. When faced with the potential for loss and cognitive decline, these participants acknowledged those potentials and had chosen to move forward. Lastly, “the future is measured by pivotal moments” could be related back to social positions (Bartlett & O’Connor, 2010) where individuals roles were identified among their close family and friends, and the need for support was illuminated.

6.5 Theoretical Implications

People living with dementia do believe that they have a future. Their perceptions have been, and will continue to be shaped as they live their lives. Their sole focus is not to look ahead for what could come, but rather to recognize the potential for change and live in the present and enjoy life. This was exemplified as two different conceptualizations of their future 1) the present future; 2) the distant future. There were many factors that could contribute to the ability of an individual living with dementia to perceive the future as positive rather than negative. Support of family, engagement and positive coping strategies all helped to create a positive outlook on the future.

The present future focussed on what the individual with dementia was able to do to incorporate their diagnosis into their life and move forward with their day to day. Lastly, the distant future was focussed on loss of abilities and capacity and included their relationship to others. Studies that depicted the fear of being a burden (Alzheimer Society of Canada, 2019a; Clarke et al., 2012; Johannessen & Möller, 2013) further exemplified that relationships require examination to determine how they are able to empower or disempower those living with dementia (Wiersma et al., 2016) and its impact on their perceptions of the future. The distant future was measured by pivotal moments such as transitioning into long term care, and it is important to understand how people in their lives are able to support them.

6.6 Implications for Practice

The development of a resource pamphlet outlining the important aspects that could influence people with dementia's perceptions of the future is important. It was evident that empowering these individuals, being connected and engaged all had positively influenced their perceptions of the future. It is crucial to take into consideration the biographies of individuals with dementia when they are diagnosed and starting on their journey with this condition. However, streamlining this process so that it could be adopted by health care practitioners and family is important. Having a guide for health care practitioners and family care partners could aid in starting important conversations. Topics such as the importance of family support and engagement are crucial. This could aid in supporting an individual diagnosed with dementia and positively influence their perceptions of the future. Practitioners should encourage patients to focus on the present future rather than just the distant future and potential decline. The present future described one's ability to incorporate dementia into their day to day life. This allows people living with dementia to continue being engaged in what brings them joy, and ultimately live a fulfilled life.

Lastly, the notion that exemplifying stories of people living well with dementia being detrimental to receiving funding (Beard, 2004a) is important to address. It was evident in this research that although these individuals are living well, they do still face challenges. More importantly, their conditions can be more challenging when people are unaware of what living with dementia means. By allowing those with dementia to speak up and campaign on their own behalf for funding that goes towards programming and support, we will be much further along in combating stigma and moving away from only placing emphasis on cause and cure research.

6.7 Implications for Future Research

Future research needs to be done to further illuminate particular aspects that could influence people's perceptions of the future living with dementia. Topics such as relationships could be studied in depth to distinguish between types of support and the ability of someone to facilitate the independence of a loved one living with dementia. More specifically, distinguishing between relationships with others who have the same diagnosis versus without and how that alone impacted their perceptions of the future. Additionally, future research is needed that goes more in depth into what the present future versus the distant future means to those living with dementia. It was evident that there was a balance between living the day to day—incorporating the changes associated with dementia into their daily lives so they could continue living fulfilled lives—and the distant future where they perceived loss of ability and cognitive decline. For the participants of this study, neither future concept had negatively impacted their perceptions of the future overall, but this may not be the case for all those diagnosed with dementia. A broader focus needs to be placed on the meaning of time for people living with dementia and its impact on their perceptions of the future. Paying specific attention to different concepts of time will provide a more in-depth analysis into how the perceptions of people living with dementia have been or will be influenced. Identifying the most common concepts of time that these individuals identify with could also be important when addressing their perceptions of the future.

In addition, advance care planning was addressed in the literature as a potential topic of discussion when asking people about their future. Dementia has no cure, therefore some background as to how they could have been involved in advance care planning was important if they brought it up during the study. I believed that shying away from this topic would only further stigmatize death and end of life. In seeing how perceptions of the future were influenced by the various interpretations of time, end of life would be an interesting component to examine more specifically. Directly asking participants about their perceptions of end of life could illuminate different meanings and uses of time such as calendar and clocked time identified by (Jowsey, 2016). In addition, this research sought to understand how people living with dementia's perceptions of the future were shaped, and one of those proposed ways was potential personality characteristics that aided in coping (Kitwood, 1997b). However, it is important to note that this was not something that was evident to me in this research. Future research that aimed to delve deeper into personality characteristics and their influence on one's ability to cope—

and subsequently how it impacted their perceptions of the future—would have to take a much more focussed approach to asking questions that would illuminate such characteristics. The scope of this project was too broad to examine or draw conclusions about such finite aspects of these individuals' personalities.

Lastly, further research could incorporate more diverse demographics of individuals different than the ones represented in this research. These individuals were arguably empowered and willing to share experiences based on the advocacy groups they were recruited from. Moreover, particular attention could be paid to gender, race, and socioeconomic status as well as geographic region to compare and contrast the experiences of those individuals.

6.8 Limitations

Firstly, it is important to address the sample bias of this study. Participant demographics were not a focus of this research as it was an exploratory study that sought to fill gaps in literature around people with dementia's perceptions of the future. For instance, gender was not considered and only one participant in this study was female. Furthermore, all participants were recruited from the same geographic location and their socioeconomic status, race and religion were not a focus.

In addition, my involvement in the organizations that participants were recruited from may have impacted the findings of this study. Rapport was argued to be important as the nature of topics about the future living with a chronic condition were sensitive. Moreover, participants may have felt more comfortable sharing personal experiences, rather than general statements about living with dementia. As much as this could be seen as a benefit to this study, it could also be argued to have created bias. Due to the prior relationship with participants, researcher bias was something that had to be carefully considered during analysis of the data. Lastly, it is important to consider that these individuals were all recruited from places that encouraged advocacy, especially from those with lived experience of dementia. This may have influenced their desire to participate in research as they felt empowered to share their stories because it was something they had done previously.

Future research should consider the impact of participant demographics to create a study that reflects a broader demographic of people living with dementia and elucidate similarities and differences among those groups. It would also be beneficial to see if there was a difference in the depth of data collected when the researcher had no prior relationship to the participant group.

6.9 Knowledge Translation

The dissemination of results will incorporate visual aids such as posters and pamphlets, that aim to inform people with dementia, their families, and care providers of what the most important aspects of the future are to people living with a diagnosis. A published report will contribute to existing literature, by solely reporting on the experiences of people living with dementia. Being an active participant in thinking about one's future, and acting on those perceptions is an essential component of living well. This research identified some of the most important aspects of the future from the perspective of people living with dementia.

Although I intend to publish portions of this research, I wish to reach other audiences. Primarily, I want the findings to be accessible to people who have been diagnosed with dementia. I believe that the statements of my participants could be encouraging to others to accept their diagnosis and know that their futures are bright, and they are important. At my last focus group, I mentioned this to my participants and they were all interested in helping me create a document that could be used to disseminate the findings in a succinct way. After this research has been submitted and finalized I will work to create a document (most likely a pamphlet) and take it back to my participants for their input. I hope that this document might be available in settings where people who have received a diagnosis of dementia, particularly those who have received it recently, so they are able to hear the stories of those that are living fulfilled lives.

Chapter 7: Conclusions

The purpose of this research was to explore people with dementia's perceptions of the future since receiving their diagnosis. I sought to understand how their perceptions were shaped by people in their lives (family, care partners, friends, community, services and supports) (Bury, 1982), potential personality characteristics that aided in coping (Kitwood, 1997b), experiences in social environments such as stigma, past history, and a variety of other factors (Beard, 2004b). When structuring my focus groups, I had organized them as the past, the present, and the future to see how their experiences over time had potentially influenced how they thought about the future. It became clear that the concept of time was something that needed to be explained in order to see how these individuals have been able to cope with their diagnosis. Participants were unable to isolate those periods of time when discussing how they were living with a diagnosis of dementia. They were continually referencing their pasts, in both discussions about the present and the future.

In an attempt to delve into what the future meant to someone living with dementia I came to realize that it was an abstract concept. The future was not simply something far down the road that they had made plans for. Rather, participants talked mostly about taking things day by day and referenced the future in statements about continuing what they were already engaged in (i.e. activities, being with friends/family, etcetera). Although I had planned for possible discussions about end of life or palliative care, it was evident that this was not a focus of these participants. They did not naturally bring it up in conversation so I chose not to ask them because I wanted their perceptions of the future, not what they thought about certain potential aspects that may be characteristic of a chronic progressive condition. People's perceptions of the future could be argued to have changed since receiving their diagnosis. Participants readily discussed their potential for decline and challenges they were already facing. Some of that meant the loss of their ability to do things (driving, skiing, hiking, etcetera) but all had found ways to adapt. Generally, their perceptions of the future had not drastically changed. Furthermore, participants felt that they thought no differently about their future than those without a diagnosis of dementia.

“Making the best of it” was another evident theme that emerged out of this research. This required the individual to acknowledge a limitation. Once that happened, they were able to draw on past experiences and social networks for support. These individuals placed an emphasis on learning from their past experiences of watching others live with dementia as well as other chronic conditions. They took away lessons of perseverance, as well as remaining socially and physically active, and ultimately keeping a positive mindset. Their families and friends were crucial in empowering and facilitating their engagement in activities that brought them joy. All participants talked about the continuation of activities and the importance of family in moving forward.

Participants identified past experiences with stigma as well as the reasons they believed those living with dementia were continually stigmatized. The label of dementia is often misunderstood. These individuals believed that this lack of knowledge contributed to forms of stigma that revolved around misconceptions about their condition. Making assumptions about their abilities was the most prominent form of stigma participants experienced in the present. Even though these individuals’ focus was not on the future (if one conceptualized it as planning for what has yet to happen) they did consistently talk about continuing to live their lives. Therefore, there was a distinction made between two different types of futures: the present future and the distant future.

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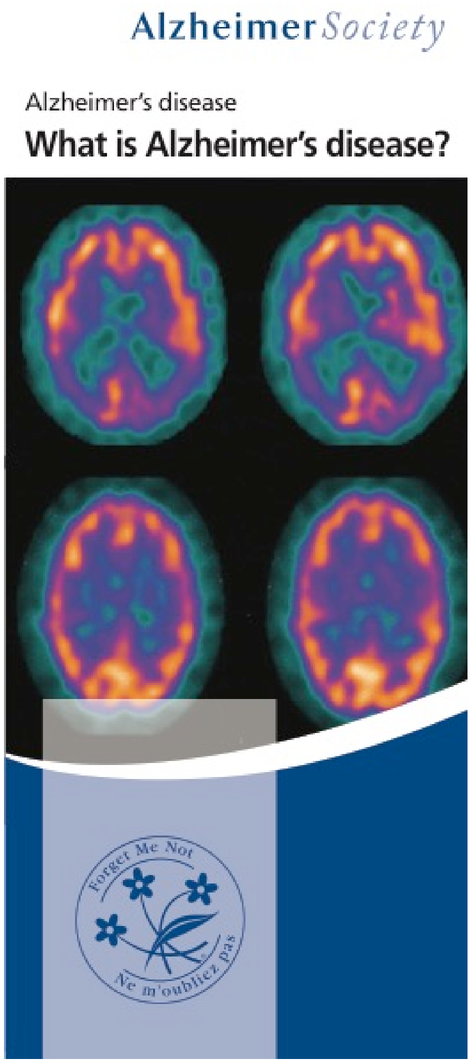
Appendices

Appendix A - Alzheimer's Disease Pamphlet

https://alzheimer.ca/sites/default/files/files/national/core-lit-brochures/what%20is%20ad%20%28en%29.pdf



AlzheimerSociety

Alzheimer's disease

What is Alzheimer's disease?

Forget Me Not

Ne m'oubliez pas

Appendix B - NICE Capacity Framework

http://www.nicenet.ca/files/NICE_Capacity_and_Consent_tool.pdf

PART II: DECISIONAL MENTAL CAPACITY AND CAPACITY ASSESSMENT

1 WHAT IS DECISIONAL MENTAL CAPACITY?

- Legal Definition NOT Clinical Definition
- Different legal definition in different jurisdictions (ie. different provinces, different countries)
- Assessment of capacity for treatment refers to a LEGAL assessment NOT a clinical assessment
- Not tested by the Mini-Mental Status Test (MMSE)
- Clinical assessments underlie diagnosis, treatment recommendations and identify or mobilize social supports
- Legal assessments remove from the person the RIGHT to make autonomous decisions in specified areas
- Legal Assessments look at Decisional Ability to make a Particular decision (ie Capacity in respect to particular treatment, Capacity to handle property, Capacity in Respect to admission to long-term care, Capacity to make personal care decisions about shelter)

(credit to workshop slide by Dr. Janet Munson)

2 LEGAL DEFINITION OF CAPACITY IN RESPECT TO TREATMENT, ADMISSION TO CARE FACILITIES, AND PERSONAL ASSISTANCE SERVICES

Health Care Consent Act s.4

Two step definition

1. Able to understand the information that is relevant to making a decision about the treatment, admission, or personal assistance service as the case may be, and
2. Able to appreciate the reasonably foreseeable consequences of a decision or lack of decision

3 PRESUMPTION OF DECISIONAL CAPACITY

HCCA s.4
Person presumed to be capable for treatment, admission to care facilities and personal assistance services.

Exception
Person entitled to rely on presumption **UNLESS** he or she has reasonable grounds to believe the other person is incapable in respect to treatment, admission to care facilities, personal assistance services as case may be.

HCCA s.15

- May be capable in respect to some treatments and incapable in respect to others.
- May be incapable with respect to treatment at one time and capable at another

4 ASSESSMENT OF DECISIONAL CAPACITY *

Need to assess:

1. Ability to Understand (factual knowledge + problem solving ability)
2. Ability to Appreciate (realistic appraisal of outcome + justification of choice)

Understand - 1st Base

- Factual knowledge: preservation of old skills & knowledge
- Has the person had learning opportunities to acquire the relevant facts:
- Updated information re: medical status, new risks or limits in ADL functions?
- Does the person understand what treatment is being offered - what it is, benefits of it, risks,

Understanding Options - 2nd Base

- Able to comprehend information about options, risks to make an informed choice
- Able to attend to relevant stimuli, understand at conceptual level and retain essential information long enough to reach a decision
- Able to remember prior choices and express them in a predictable and consistent manner over time
- Able to problem solve around personal issues-probe specific examples

Appreciate - 3rd Base

- Able to appraise potential outcomes of a decision
- Focus on reasoning process, explore the personal weights, values attached to each outcome
- Acknowledges personal limitations/show insight
- Decision-making is reality-based, not being affected by delusions (fixed false beliefs) or skewed by emotional states (depression, hopelessness causing an undervaluing of survival issues).

Appreciate - 4th Base

Justification of choice:

- Shows evidence of rational (based in reality) manipulation of information - a "reasoned choice", not necessarily a reasonable choice
- Grounded in personal beliefs and values consistent with previous actions, expressed wishes, cultural or religious beliefs

(credit to workshop slides by Dr. Janet Munson)

A pdf file of this tool is available
on the NICE web site or you may contact
NICE directly to order additional copies.

NICE National Initiative for the Care of the Elderly
Initiative nationale pour le soin des personnes âgées
We care together
Ensemble pour le bien-être des aînés

National Initiative for the Care of the Elderly
222 College Street, Suite 106, Toronto, Ontario M5T 3J1
Tel: 416-978-2197 • Website: www.nicenet.ca

Advocacy Centre for the Elderly
2 Carlton Street, Suite 701
Toronto, Ontario, M5B 1J3
416-598-2656

2 Carlton Street, Suite 701, Toronto, Ontario, M5B1 J3
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Appendix C - Visual Aids

“The Unspoken Impact of Dementia” video

https://www.youtube.com/watch?v=z15-0xZTng4

This video speaks about the impact that stigma has on people living with dementia. The experiences of people living with a diagnosis exemplify the damaging effects that stigma can have on those living with dementia. Furthermore, it stresses the importance of education about the condition so that people living with dementia do not become isolated as a result of stigmatization.

“Agnes and Nancy” video

https://vimeo.com/32903503

Nancy and Agnes share their story about life after a diagnosis of dementia. They discuss their struggles, and how they have coped with their condition. It is a story of two individuals who are actively engaged in their lives, managing their condition and continuing to enjoy their life.

“Nancy and Agnus Discuss Living with Early Onset Dementia| Adventures in Dementia” video

https://www.youtube.com/watch?v=6xnyGfwcj7U

Nancy and Agnes reunite to share their experiences of life with dementia, and a recent trip to Ruth Bartlett’s event “Reimagining Life with Dementia”. A powerful moment between the two friends came when Agnes shared she had been advised by medical professionals that her vision was bad enough that she would be unable to safely cross the street by herself. When disclosing the news to her friend Nancy, she acknowledged the information, but quickly moved on to ask

Agnes to accompany her on a white-water rafting trip; pointing out it did not require her to cross the street. The experiences of these two friends exemplifies what it means to incorporate dementia into one's life, but not let it define them.

Appendix D - Focus Group Guide

Tell me a little bit about yourself.

- **THE PAST**

Diagnosis

- Can you tell me about the process of receiving your diagnosis of dementia?
- What helped you throughout the process? How so?
    - Family, friends, support groups, services etc.
- What did you think when you received your diagnosis?
- Did you know people who had been diagnosed with dementia before you were?
    - If yes, how did this impact your thoughts about your own diagnosis?
    - If no, do you think it would be beneficial to have known others with dementia? Why or why not?
- Other than your own diagnosis, have you had experience and/or knowledge of dementia?

- **THE PRESENT**

Coping and Adapting

- What changes have you experienced since being diagnosed with dementia?
- Since your diagnosis, how have you been processing and thinking about your diagnosis?
- What helps you to cope with your diagnosis and the changes you might be experiencing?

Relationships

- Have you experienced changes in your relationships after receiving a diagnosis?
- Have your friends/family relationships changed? Have they distanced themselves? Or have you become closer?
    - If so, how does that make you feel?

Stigma

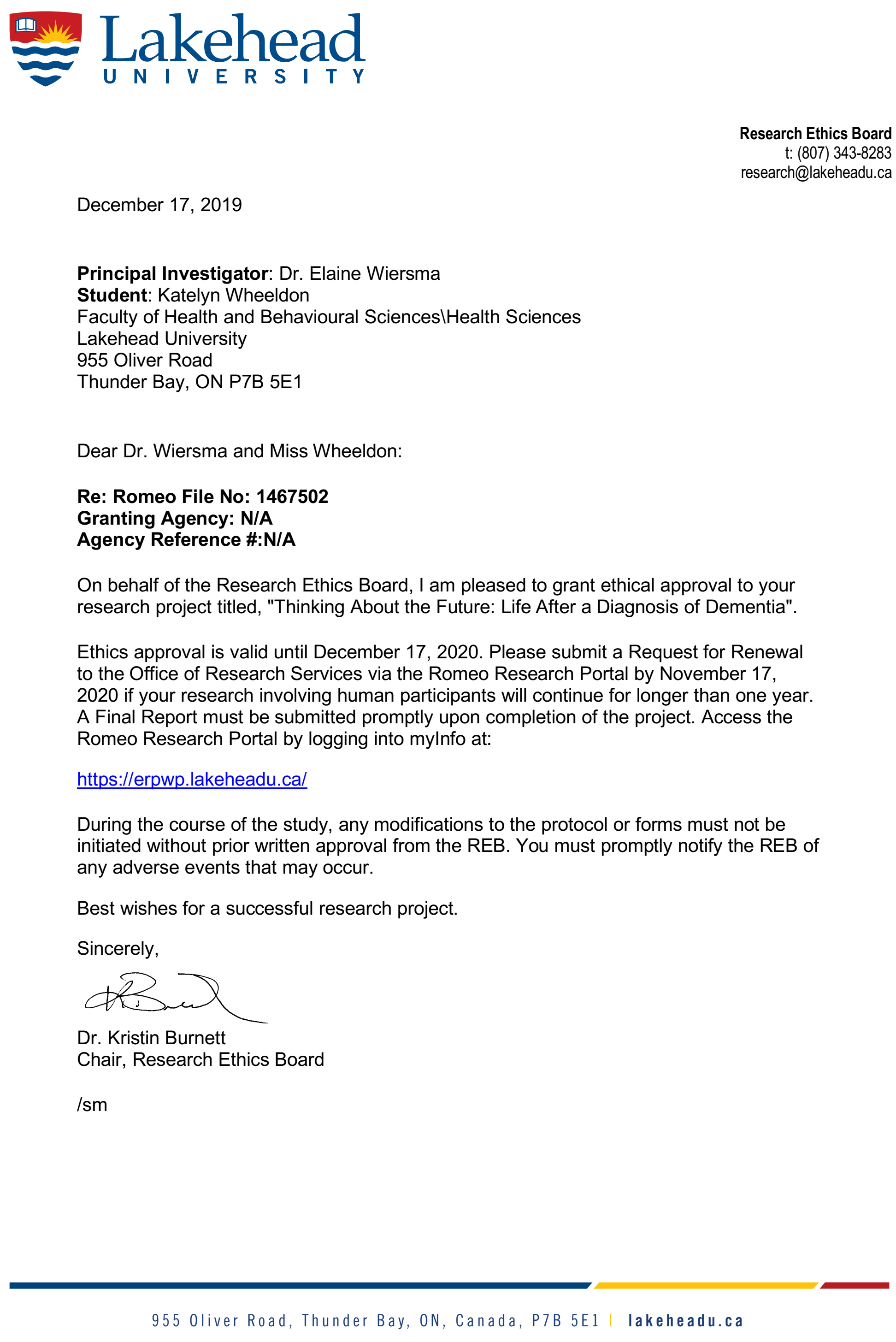
- What does stigma mean to you? Have you experienced stigma related to your diagnosis? How so? How did you respond?

- **THE FUTURE**

- What does the future mean to you?
- Has this changed since your diagnosis? How so?
- How does your coping and adapting affect how you think about the future? (refer back to themes)
- When you think about your future, who are the people who will be there? That you want to be there?
    - Family, friends
- Can you tell me why those people are important to your future?
    - If there are people not included, why? (burden?)
- How do those relationships affect how you think about the future?

- Have you talked to others about the future? If so, what have the conversations been? If not, why not?
    - Would you like to initiate those conversations, or your family, friends?
    - If so, what are the most important things you would want to talk about with them?
    - If not, why don’t you want to talk to them about the future?

Appendix E – Ethics Approval Letter



Research Ethics Board
t: (807) 343-8283
research@lakeheadu.ca

December 17, 2019

Principal Investigator: Dr. Elaine Wiersma
Student: Katelyn Wheeldon
Faculty of Health and Behavioural Sciences\Health Sciences
Lakehead University
955 Oliver Road
Thunder Bay, ON P7B 5E1

Dear Dr. Wiersma and Miss Wheeldon:

Re: Romeo File No: 1467502
Granting Agency: N/A
Agency Reference #:N/A

On behalf of the Research Ethics Board, I am pleased to grant ethical approval to your research project titled, "Thinking About the Future: Life After a Diagnosis of Dementia".

Ethics approval is valid until December 17, 2020. Please submit a Request for Renewal to the Office of Research Services via the Romeo Research Portal by November 17, 2020 if your research involving human participants will continue for longer than one year. A Final Report must be submitted promptly upon completion of the project. Access the Romeo Research Portal by logging into myInfo at:

https://erpwp.lakeheadu.ca/

During the course of the study, any modifications to the protocol or forms must not be initiated without prior written approval from the REB. You must promptly notify the REB of any adverse events that may occur.

Best wishes for a successful research project.

Sincerely,

Dr. Kristin Burnett
Chair, Research Ethics Board

/sm

955 Oliver Road, Thunder Bay, ON, Canada, P7B 5E1 | lakeheadu.ca

Appendix F- Verbal Recruitment Script

Lakehead
UNIVERSITY

Health Sciences
e: kvwheeld@lakeheadu.ca

Hello. My name is Katelyn Wheeldon. I am a student at Lakehead University. I am conducting a study about how people living with dementia think about their future. I wondered if you might be interested in participating in the project as a participant? I would like to give you some more information about the project. Would you permit me to get your name and contact information so I can contact you to explain a little bit more about the project and talk to you more about your participation? Participation is completely voluntary, and you can change your mind at any time, and this won't have any impact on your relationship here with us at [partner organization].

Appendix G -
Information Letter for Thinking About the Future: Life After a Diagnosis of Dementia

Lakehead UNIVERSITY

Department of Health Sciences
e: kvwheeld@lakeheadu.ca

Dear Potential Participants,

I would like to invite you to participate in a research project that I am conducting on how people living with dementia think about their future since receiving their diagnosis. This research is part of my thesis project for a Master of Health Sciences degree at Lakehead University under the supervision of Dr. Elaine Wiersma, Associate Professor, Department of Health Sciences.

Your participation in this research is voluntary, and before you decide whether or not you would like to take part in this study, please read this letter carefully to understand what is involved. After you have read the letter, please ask me any questions you may have.

WHO IS CONDUCTING THIS PROJECT?

- Katelyn Wheeldon, Master of Health Sciences (Gerontology) student, Lakehead University, under the supervision of Dr. Elaine Wiersma, Associate Professor, Department of Health Sciences.

PURPOSE

- I would like to learn how people living with dementia think about their future since receiving their diagnosis.

WHAT INFORMATION WILL BE COLLECTED?

- I will be collecting your responses to questions about your experience since receiving your diagnosis. Topics will include: receiving your diagnosis, coping and adapting, relationships, stigma, and what you think about your future. Focus groups will be audio recorded, and I will be taking notes on observations. This information will help us create a framework together that reflects what is most important to someone living with dementia. The framework can then be used to help other people living with dementia talk about some of these topics with their care partners.

WHAT IS REQUESTED OF ME AS A PARTICIPANT?

- You will participate in 4 focus groups which will be audio recorded. I will make notes during focus groups on interactions, comments, observations, responses to the questions, and other information as appropriate. During the first three focus groups we will discuss your opinions around topics such as receiving your diagnosis, coping and adapting, relationships (family/friends), stigma and the future. The fourth focus group will be for member checking. Member checking involves taking some of the themes I have observed away from what we have discussed, and asking you whether or not they accurately reflect your experiences. This is an important part of this study to ensure that the findings accurately represent what you think about your future.
- I may ask you additional clarification questions outside of focus groups with your permission. This means that immediately following the end of a focus group session, I may ask your permission to stay for an extra minute so I can ask you clarifying questions about something you told me during the focus group. This will ensure that my notes and analysis of what we have discussed accurately reflect your experiences.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

- You are under no obligation to participate, and are free to withdraw at any time without prejudice to pre-existing entitlements
- Your decision to participate will not affect your academic status/employment/or ability to participate in present or future services with the Dementia Café, North West Dementia Working Group, or The Centre for Education and Research on Aging & Health.
- You will be given, in a timely manner throughout the course of the research study, information that is relevant to your decision to continue or withdraw from participation
- You will be given information on the participant right to request the withdrawal of data, including any limitation on the feasibility of that withdrawal

WHAT IF I PARTICIPATE AND THEN CHANGE MY MIND?

- If you have already participated in the focus group, I will not be able to remove your personal information from the group discussions. However, all information will remain anonymous and your name/identifying information will never be attached to your experiences.

WILL THERE BE ANY RISK TO ME?

- Your decision to participate or not participate, and any decision to withdraw from the study, will have no impact on your experiences and access to present or future services with Dementia Café, North West Dementia Working Group or the Centre for Education and Research on Aging & Health.
- Because we are asking about personal experiences and how you think about your future since receiving a diagnosis, there is potential for emotional distress. In the event that you

are uncomfortable with the focus group questions, you are able to withdraw yourself. I will also provide you with information to take home on how to contact the Alzheimer Society for further support.

WILL THERE BE ANY BENEFITS TO ME?

- The benefits experienced as a result of this research are that you are free to be open and honest about your experiences. I will only be taking into consideration your experiences as a person living with dementia, so there is a unique opportunity for you to design a framework with me to help others living with the same condition talk openly about their experiences.
- In addition, you will also be designing a framework that will include the most important aspects of your future, and how to have conversations about those things with both your formal and informal care partners (family/friends/medical professionals).

WHAT WILL THIS INFORMATION BE USED FOR?

- The information gathered in this study will be used to develop a framework to guide conversations with care partners and medical professionals about the most important aspects of the future from the perspective of someone living with dementia.
- I may also be using this information to publish and make public presentations about this work, including using the findings for possible education opportunities about people's experiences living with dementia.

HOW WILL MY CONFIDENTIALITY BE MAINTAINED?

- All data will remain anonymous and all name references will be replaced by pseudonyms unless you request otherwise. Your name will never be attached to your quotes or experiences. Your quotes may be used with no identifying information attached to it.
- All information gathered throughout this study, including the audiotapes of the focus groups, will be kept strictly confidential and will only be accessed by myself (Katelyn Wheeldon) and Dr. Elaine Wiersma.
- Any identifying information will be removed in the final report and publications that may emerge from this research unless you request otherwise. All information pertaining to the study will be kept in a locked filing cabinet at Lakehead University for a minimum of five years.
- I will ask all participants to keep the responses of other members of the focus group confidential, but I cannot guarantee that other members will comply with this request.

WHERE WILL MY DATA BE STORED?

- The data will remain locked in a filing cabinet for up to 5 years at Lakehead University, after which time audiotapes will be destroyed and electronic transcripts with no identifying information may be kept indefinitely.

HOW CAN I RECEIVE A COPY OF THE RESARCH RESULTS?

- I will not be collecting your contact information as part of this study, so I will be unable to notify you directly upon completion of this study. If you wish to obtain a copy of the research results, you may contact me (Katelyn Wheeldon) at kvwheeld@lakeheadu.ca.

WHO CAN I CONTACT IF I HAVE MORE QUESTIONS?

Katelyn Wheeldon at kvwheeld@lakeheadu.ca, or Dr. Elaine Wiersma at ewiersma@lakeheadu.ca (807)-766-7294.

The findings of this research will not be commercialized, and the researchers declare no conflict of interest.

This research study has been reviewed by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone other than the researcher, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

Thank you for your interest and considering to participate in this project.

Sincerely,

K. Wheeldon

Katelyn Wheeldon
Master of Health Sciences (Gerontology) candidate
Centre for Education and Research on Aging & Health
Lakehead University

WHAT DO I NEED TO DO TO PARTICIPATE?

If you agree to voluntarily participate, and you have read and understood the above information (including the risks and benefits of the research), please check and sign below:

- ☐ I have read and understand the information contained in the Information Letter
- ☐ I agree to participate
- ☐ I understand the risks and benefits to the study
- ☐ That I am a volunteer and can withdraw from the study at any time, and may choose not to answer any question
- ☐ That the data will be securely stored at Lakehead University for a minimum period of 5 years following completion of the research project
- ☐ I understand that the research findings will be made available to me upon request
- ☐ I will remain anonymous
- ☐ All of my questions have been answered

By consenting to participate, I have not waived any rights to legal recourse in the event of research-related harm.

Participant name (printed):

Signature:

Date:

Researcher Signature:

Health Sciences
e: kvwheeld@lakeheadu.ca

Appendix H - Verbal Consent Script

Before beginning this focus group, I would like to remind you about the purpose of this study, your participation and ability to withdraw your consent at any time. This research is to determine how people living with dementia think about their future since receiving a diagnosis, and what has influenced those perceptions. You are consenting to participate in focus group interviews, and may be asked by (Katelyn Wheeldon) to answer additional clarifying questions about your experiences individually. All interviews are audio recorded. You are able to withdraw your consent at any time, and it will have no impact on your involvement at Dementia Café, CERAH, or the North West Dementia Working Group.

Appendix I - Focus Group Guide (Amended)

*read verbal consent script
Tell me a little bit about yourself.

- **THE PAST**

Diagnosis

- Can you tell me about the process of receiving your diagnosis of dementia?
- What helped you throughout the process? How so?
    - Family, friends, support groups, services etc.
- What did you think when you received your diagnosis?
- Did you know people who had been diagnosed with dementia before you were?
    - If yes, how did this impact your thoughts about your own diagnosis?
    - If no, do you think it would be beneficial to have known others with dementia? Why or why not?
- Other than your own diagnosis, have you had experience and/or knowledge of dementia?

- **THE PRESENT**

Coping and Adapting

- What changes have you experienced since being diagnosed with dementia?
- Since your diagnosis, how have you been processing and thinking about your diagnosis?
- What helps you to cope with your diagnosis and the changes you might be experiencing?

Relationships

- Have you experienced changes in your relationships after receiving a diagnosis?
- Have your friends/family relationships changed? Have they distanced themselves? Or have you become closer?
    - If so, how does that make you feel?

Stigma

- What does stigma mean to you? Have you experienced stigma related to your diagnosis? How so? How did you respond?

- **THE FUTURE**

- What does the future mean to you?

- Has this changed since your diagnosis? How so?
- How does your coping and adapting affect how you think about the future? (refer back to themes)
- When you think about your future, who are the people who will be there? That you want to be there?
    - Family, friends
- Can you tell me why those people are important to your future?
        - If there are people not included, why? (burden?)
- How do those relationships affect how you think about the future?

- Have you talked to others about the future? If so, what have the conversations been? If not, why not?
    - Would you like to initiate those conversations, or your family, friends?
    - If so, what are the most important things you would want to talk about with them?
    - If not, why don't you want to talk to them about the future?

- **MEMBER CHECKING**

- Does (insert theme) accurately reflect your experience when thinking about (your diagnosis OR coping and adapting OR your relationships OR stigma OR your future)?
        - Is there anything else that you would like to add to (insert theme)?
        - Is there anything you would like to clarify about (insert theme)?
- Do you believe that you think about the future differently than others who have not been diagnosed with dementia?
        - If so, how? If not, why not?
- What kind of plans have you made for the future?
- Do you think other people underestimate your abilities?
        - How does this make you feel?
- What has helped you accept your diagnosis?
        - i.e. family, friends, remaining active, past experience
        - how does accepting your diagnosis impact your perception of the future?
- What does independence mean to you?
        - How can others support it?
- How has connecting with other people living with dementia affected you? Your perception of the future?

*get permission to ask participant clarification questions (if needed)

- Clarification questions (immediately following a focus group):
    - Does (insert my (K.Wheeldon) understanding of what they said during focus group) reflect what you discussed during the focus group?
    - What did you mean when you said (insert point they made during a focus group)?
    - Is there anything you would like to add?